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South Asians in the United Kingdom and Specialist Services

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This thesis is submitted in partial fulfilment
of the requirements for the degree of
Doctor of Clinical Psychology

Coventry University, Faculty of Health and Life Sciences and
University of Warwick, Department of Psychology

May 2011

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Acknowledgements

I would firstly like to thank the South Asian women who shared their experiences of their cancer journey with me for the benefits of this study, without them, this study would not have been possible. I would also like to thank the staff members that took time out from their busy schedules to provide their professional perspectives.

Thank you to my academic supervisor Dr. Helen Liebling-Kalifani and my clinical supervisor Dr. Shradha Lakhani, for both of their support and guidance from the beginning.

In addition, I would like to thank Dr. Jo Kucharska, Dr. Mary Deane and Lis Boyde for their comments on the drafts of chapters.

Thanks to my all family and friends for their support and patience during the past three years. To the fantastic supportive friends in the cohort, the laughter in the postgraduate room I shall never forget.

To my sister and best friend, Heena, a great big thank you for cheering me up on the days when I thought I could not continue and for believing in me.

A special thank you to my husband, Krishan for being there by my side through it all, words cannot express my gratitude. You are my rock.

Finally, gratitude to the woman who had supported me from the moment I decided to embark on this career, my Mum. Thank you for all that you have done for me. This thesis is dedicated to you.

Declaration

I declare that this thesis is my own work based on collaborative research and that the thesis has not been submitted for another degree at another university.

Summary

Chapter one is a literature review of the psychosocial factors which influence alcohol use in British South Asian men. Critical analysis of fourteen research articles revealed differences between first and second-generation South Asian men. The influence of religion, parental beliefs and acculturation were reported within the literature to affect alcohol use. The literature highlighted the issue of stigma and lack of awareness of services as barriers for treatment seeking. Additionally, the effect of religious and cultural beliefs of alcohol use may also discourage support from services.

Chapter two investigated the experiences of British South Asian women who accessed psychological treatment within a cancer service using in-depth semi-structured interviews. Key informants participated in focus groups to gain experiences of staff who had worked with South Asian communities. Using Interpretative Phenomenological Analysis, the findings elicited themes which illustrated that the South Asian women held pre-existing beliefs about psychological services. They also described their psychological journey of cancer treatment and the impact on their family, friends and differences between generations was reported. Analysis of the key informants' focus group data highlighted the theme of challenges faced by the South Asian patients and the staff. This article provided evidence for better education and awareness for South Asian communities and staff.

Chapter three is a reflective article on the process of conducting the empirical research. The article addressed the reasons that influenced the researcher to conduct the study. Issues that had arisen were of the effect of 'sameness and difference' between the researcher and participants and the impact of qualitative research methodology and empowerment. A reflection of the impact from the interview accounts was also discussed.

Abbreviations

ASSIA	Applied Social Sciences Index and Abstracts
AUDIT	Alcohol Use Disorders Identification Test
BME	Black Minority Ethnic
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DOH	Department of Health
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
ONS	Office for National Statistics
SADQ	Severity of Alcohol Dependence Questionnaire
UK	United Kingdom

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Chapter One: British South Asian Men and Alcohol Use: A Literature Review

Word count (excluding, title, table and references): 7,891

Article prepared for submission to Journal of Ethnicity in Substance Abuse (See appendix 1 for notes to contributors)

1.1 Abstract

This article reviewed the recent literature on British South Asian men and the psychosocial factors, which influenced alcohol use. Fourteen articles, which discussed alcohol use in British South Asian men, aged 16 years and over, were coded and critically analysed. The studies used qualitative and quantitative methodology. Psychological and social factors were investigated to include education, religion, parental effects, acculturation, emotional regulation, identity, masculinity, social support, and generational differences. Treatment seeking barriers were limited awareness of services and stigma. Methodological limitations of the research literature were discussed. Implications for treatment services and future research are discussed.

Keywords: South Asian men, alcohol use, psychosocial factors.

1.2 Introduction

The increasing rate of alcohol misuse in the United Kingdom (UK) is a key concern for the government, as alcohol related illnesses cost the National Health Service (NHS) approximately £2.7 billion between 2006 and 2007 (Department of Health, 2009). Despite abstinence levels being high amongst Black Minority Ethnic (BME) groups, differences within and between ethnic groups exist and alcohol consumption rates are likely to increase in specific BME groups (Hurcombe, Bayley, & Goodman, 2010). Rasool (2006) stated that due to poorer social, psychological, environmental, and economic circumstances compared to the White British population, BME groups are at a greater risk for alcohol and substance abuse. Although the vulnerabilities of the BME population are known, BME groups face difficulties in accessing alcohol treatment services (Strategy Unit, 2004) and services fail to meet the needs of problem alcohol use within BME groups (Alcohol Concern, 2002).

The majority of the British South Asian community have reported to abstain from alcohol however; small-scale studies have highlighted heavy alcohol consumption in some South Asian men (Cochrane & Bal, 1990; Heim, Hunter, Ross, Alastair, Bakshi, Davies, & Flatley, 2004; McKeigue & Karmi, 1993; Orford, Johnson, & Purser, 2004). Therefore, this article aimed to explore the psychological, social and cultural factors which influenced the differential patterns of alcohol use and the barriers to treatment in South Asian men living in the UK. Additionally the article identified the implications for clinical services and makes practical recommendations for those working in this field.

1.2.1 South Asians in the UK

According to the Office for National Statistics (ONS) 2001 census, the South Asian community is the largest ethnic group and approximately 2.3 million South Asians are living in the UK (ONS, 2001). For the purposes of this review, the term 'South Asian or Asian' (used interchangeably) defines a person who identifies their ethnic group and cultural background to originate from India, Pakistan or Bangladesh (ONS, 2001). Within the UK, individuals identifying themselves as Indian, represented 51% of the South Asian category, followed by 35% as Pakistani and 14% as Bangladeshi (ONS, 2001). South Asians living in the UK originally migrated from India, Pakistan, and Bangladesh and some groups migrated from East Africa (Modood, 1997). The distinct South Asian subgroups which are residing in the UK include Gujarati Hindus, Punjabi Sikhs, and Muslims from India, as well as Muslims from Pakistan and Bangladeshi (McKeigue & Karmi, 1993; Modood, 1997). Rasool (2006) highlighted that the South Asian community were a heterogeneous group with diverse religious and cultural beliefs who have settled in various regions of London, the Midlands, and northern cities (Modood, 1997).

1.2.2 British South Asian male alcohol consumption

In general, alcohol consumption rates in the South Asian community have been reported to be lower than in the general White British population (Hurcombe et al., 2010; Rasool, 2006). Literature reviews which investigated South Asian alcohol use have highlighted gender differences in consumption patterns. Men in South Asian groups reported high alcohol use and high levels of alcohol related problems (McKeigue & Karmi, 1993; Hurcombe et al., 2010). National surveys have found that 66% of Indian men reported to have consumed alcohol compared to 8% and 3% of Pakistani and Bangladeshi men, respectively (Erens, Primatesta, & Prior, 1999;

Nazroo, 1997). On a cautionary note, Pannu, Zamman, Bhala, and Zamman (2009) reported there was limited evidence based on alcohol use in South Asian men in the UK and stated that the existing data was inconsistent due to the different categorisation of Asian subgroups. Thus, they suggested that there is a misconception that all South Asians consumed low amounts of alcohol and had low alcohol related mortality.

Over half of the UK born Indian men sampled consumed slightly less alcohol per week compared to White British men (Orford et al., 2004; Heim, et al., 2004). The average weekly consumption for UK born Indian men was 8.83 units per week, which is lower than the UK government recommended twenty-one units per week allowance (Department of Health, 2007) and any consumption above this was regarded as excessive within the review. However, non-UK born Sikh men consumed the highest amounts of alcohol out of all migrant South Asian groups, they drank approximately twelve units per week, and some reported drinking on average over thirty units per week (Cochrane & Bal, 1990; McKeigue & Karmi, 1993; Vora, Yeoman, & Hayter, 2000). UK born and migrant Muslim, Pakistani and Bangladeshi men were mostly abstinent from alcohol. However, approximately 20% of the UK born and migrant Pakistani and Muslim men sampled reported to have consumed approximately 16.28 units per week (Orford et al., 2004; Heim et al., 2004; Vora et al., 2000; Cochrane & Bal, 1990; McKeigue & Karmi, 1993). Wanigaratne, Dar, Abdulrahim, and Strang (2003) suggested differences in alcohol consumption within South Asian groups might be explained by the acceptance of alcohol by the differing religious and cultural beliefs which existed within the South Asian communities. Therefore, investigation by individual religious and ethnic groups is warranted. These findings highlighted the subtle differences between the

different ethnic and religious groups within South Asian men living in the UK.

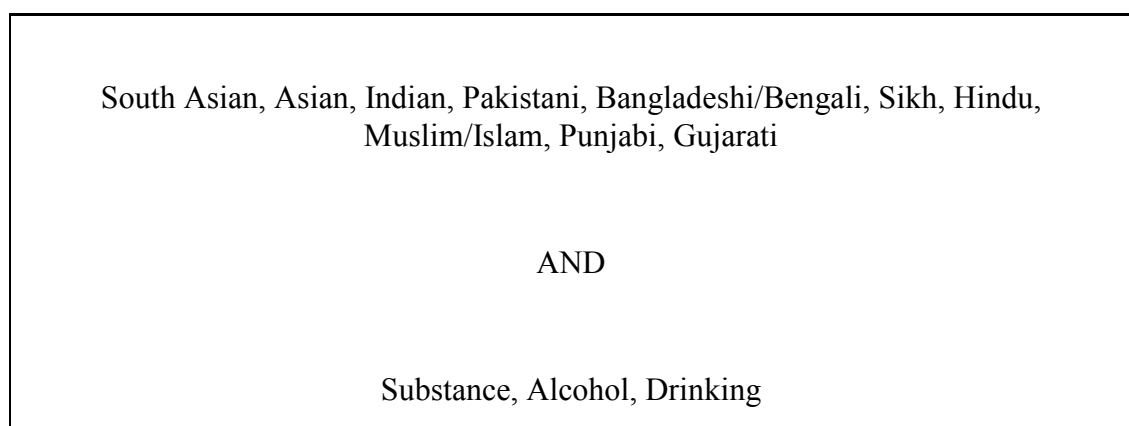
Given the differential patterns of alcohol use, this literature review aimed to highlight the psychological and social factors which influenced alcohol consumption in South Asian men.

1.3 Method

The literature search was conducted by searching six internet databases (ASSIA, PsycArticles, PsychInfo, Medline, CINAHL, and Web of Knowledge) to find peer reviewed journal articles which examined alcohol use in British South Asian males from the last 20 years. The databases were searched using key terms found in box 1 (see below). The terms were searched in journal article abstracts, titles, and keywords. The overall search resulted in 1084 peer reviewed articles. All articles were screened and were included if they met the following inclusion criteria:

1. The study used a South Asian male sample aged 16 and over.
2. There was a focus on alcohol use.
3. The study examined psychosocial factors related to alcohol use.

Figure 1. Key search terms



This resulted in 33 articles. Further, a number of these articles were excluded for this review if they sampled South Asians from non-UK countries e.g. North America. On detailed examination of the remaining articles, additional articles were excluded where a sample included a larger percentage of female than male participants. Once relevant articles were identified, their reference lists were searched using the same search terms for additional articles. The search process was repeated until April 2011 and no additional unique articles were identified through this process. Fourteen relevant articles were found and each article was coded based on design, methodological approach, sample size, characteristics of sample, age range, measures used and the main findings. The articles included in the review are presented below in table 1.

Table 1. Summary of reviewed articles

Study	Design	Methodology	N	Sample characteristics	Age (years)	Measures	Main findings
Ahuja, Orford & Copello (2003)	Interview with wives, daughter and South Asian men who accessed alcohol services	Qualitative (grounded theory) and quantitative	41	British Sikh Male and Females first and second generation West Midlands	17-64	Coping questionnaire Semi-structured interviews Three assimilation indices	Sikh men did not recognise they had an alcohol problem. They did not acknowledge their alcohol use had an effect on their wives and daughters and they felt wives were unsupportive.
Bradby & Williams (2006)	Follow up study to compare substance use rates and reasons for abstinence	Quantitative Longitudinal study, follow up	492	Muslim, Sikh/Hindu, Christian, Male and Female, second generation Glasgow	18-20	Interviewer led questionnaire	Muslims are least likely to report alcohol consumption and there was little increase in consumption rates from this group. Sikh/Hindu males showed an increase in alcohol consumption. Religion is a strong protective factor from alcohol consumption during adolescent-adult transition.

Study	Design	Methodology	N	Sample characteristics	Age (years)	Measures	Main findings
Bradby (2007)	Investigation of young Asian substance use in relation to religion and culture	Qualitative	47	India and Pakistan (from Punjab) Male and Female, second generation Glasgow	16-26	19 semi-structured interviews (5 individual and 14 focus groups from community/peers)	Muslim alcohol abstinence is linked to religious identity. Young men's reputations are balanced by parent's reputation.
Brar & Moneta (2009)	Investigation of negative emotions and alcohol consumption	Quantitative	300	150 White 150 Indian (Sikh and Hindu) Male and Female second generation university students	18-33	Alcohol Use Disorders Identification Test (AUDIT) Hospital Anxiety and Depression Scale (HADS)	No association was found between alcohol consumption and emotion regulation within an Indian sample.
Cameron, Manik, Bird & Sinorwalia (2002)	Exploration of factors related to spontaneous alcohol recovery	Qualitative	20	Hindu, Sikh, Muslim, (60% first generation) White, males Leicester	29-60	Semi-structured Interview Severity of Alcohol Dependence Questionnaire (SADQ)	Spontaneous remission was linked to impact on religious social supports and family status and honour.

Study	Design	Methodology	N	Sample characteristics	Age (years)	Measures	Main findings
Cochrane & Bal (1990)	Investigation of alcohol use in South Asians by generation and country of birth	Quantitative	800	Sikh, Muslim, Hindu White First & second generation males Wolverhampton & Birmingham	17 – 65	Questionnaire Langner mental health questionnaire	Sikh men drink similar amounts to White men. A minority of Muslim regular drinkers consumed highest units of alcohol. Older first-generation Asian men drank more than younger men. More Sikh men reported alcohol related problems.
De Visser & Orford (2007)	Exploration of masculine identities and alcohol consumption	Qualitative IPA analysis	31	Community sample White, Black and Asian Male, second generation, London	18-21	Individual interviews and group discussions	Drinking equates to being masculine mostly in White men. Non-drinkers and Muslim men stated that a masculine identity includes rationality and independence. This group were also more likely to question the association of masculinity and alcohol consumption.

Study	Design	Methodology	N	Sample characteristics	Age (years)	Measures	Main findings
Dhillon & Ubhi (2003)	Experience of life in Britain and use of therapy in alcohol service users	Qualitative IPA analysis	32	Indian-Punjabi-Sikh Male, second generation West Midlands	28-40	Marginality questionnaires Semi-structured interviews	All participants had a marginal acculturation state. This marginal state was linked to harmful behaviours e.g. alcoholism.
Heim, Hunter, Ross, Bakshi, Davies, Flatley & Meer (2004)	Investigation of alcohol issues and perceptions of services	Quantitative	174	Pakistani, Indian and Chinese, Male and female, second generation Greater Glasgow	16-25	Interview questionnaire	Consumption rates in Asians was lower than the general population. The predictive factor for alcohol consumption was having friends who drank from the same ethnic group and that high importance of religion was negatively associated with alcohol consumption.
Morjaria & Orford (2002)	Exploration of spiritual and religious recovery from alcohol	Qualitative Grounded theory	10	South Asians (two Sikh, three Hindu), five White, male	36 (mean age)	Semi-structured interviews	South Asian men used reaffirmation of religious beliefs to help their recovery.

Study	Design	Methodology	N	Sample characteristics	Age (years)	Measures	Main findings
Morjaria-Keval (2006)	Clarify religious and spiritual aspects involved in recovery from alcohol problems	Qualitative Grounded theory	15	Sikh males Birmingham, Coventry and Leicester	No Age data	Interviews	Three stages of recovery were reported to include catalyst, commitment and maintenance.
Orford, Johnson & Purser (2004)	Exploration of alcohol drinking in second-generation South Asians	Quantitative	1684	Black, Hindu, Sikh, Bengali, Pakistani, Male and female, second generation Birmingham and Leicester	18-40+	Interviews	Sikh men's heavy drinking rates were comparable to the general population. Hindu, Pakistani and Bangladeshi men were mostly abstinent. Low religious identity correlated to alcohol consumption. Most parents did not know about their son's drinking. There was a reluctance to seek professional help.

Study	Design	Methodology	N	Sample characteristics	Age (years)	Measures	Main findings
Spada & Moneta (2004)	Investigation of negative emotions and alcohol use	Quantitative	239	120 British Asian and 119 British White Males and females undergraduate university students	18-30	HADS Quantity frequency Scale (QFS)	There was no relationship reported between negative emotions and quantity of alcohol use in British Asians.
Vora, Yeoman & Hayter (2000)	Investigation of alcohol, paan, and tobacco use and knowledge of health consequences	Quantitative	524	262 Hindu, 101 Sikh, 111 Muslim and 55 Jain, males first and second generation, Leicester	19-52	Questionnaire	Sikh males drank the most and a small number of second generation Muslims drank 18 units per week. Sikh migrant males had lowest awareness of alcohol related health problems.

1.4 Results

In total, fourteen articles were included in the literature review. Seven of the articles used a quantitative methodology, and the remainder used a qualitative or mixed methods approach. Nine of the studies reviewed investigated other ethnic groups (e.g. White, Chinese and Black) and four studies solely examined South Asian groups. Most of the studies used interviewer led questionnaires or included semi-structured interview measures or focus groups. Six of the studies incorporated standardised questionnaire measures. The age range of the South Asian men included in the review ranged from 16-57 years. The studies explored various psychological and social factors which influenced alcohol use including, education, religion, parental effects, acculturation, emotional regulation, masculinity, and social support. Each of the factors was discussed in relation to alcohol use in first and second-generation South Asian men living in the UK.

1.4.1 First Generation South Asian men

1.4.1.1 Culture.

The literature highlighted that Sikh men born in India were most likely to drink alcohol regularly and they were heavy drinkers (Cochrane & Bal, 1990). This section focused on the factors which influenced alcohol consumption in first-generation Sikh men.

Cochrane and Bal (1990) studied a sample of South Asian men living in the West Midlands. The authors used questionnaires to investigate the rates and patterns of alcohol use. The study highlighted that Sikh men drank regularly and on average consumed 25.4 units per week. Further, those Sikh men born in India drank more than those born in the UK. Additionally they found that older Sikh men drank more

alcohol than younger Sikh men. The Cochrane and Bal (1990) study noted that older migrant Sikh men reported more problems associated with alcohol consumption, such as memory loss and shaking hands. The authors suggested that alcohol consumption was part of their culture in India, where the men drank to socialise in communal areas with this culture transferring to the UK. This was supported by Bradby (2007), who reported that when Sikh men first migrated to the UK alone, they convened in pubs to socialise and integrate. Bradby (2007) also reported that drinking alcohol in pubs became less necessary and acceptable when the men formed families and built community social networks. Cochrane and Bal (1990) suggested that migrant Sikh men were similar to White British working class men, as they were reported to drink alcohol for social reasons and there was a perception that alcohol was a fortifying beverage.

Cochrane and Bal (1990) highlighted that alcohol consumption was an accepted form of socialising amongst Sikh men. The authors suggested that older men from this community were continuing to drink excessively even without the presence of others and reported that Sikh men are more likely to drink alone. Despite explaining alcohol use within the Sikh migrant group, the authors did not offer any possible reasons for the excessive consumption or the reasons for drinking alone.

These findings from Cochrane and Bal (1990) were the first to highlight the differences in alcohol consumption patterns between South Asian groups. However, the study used a sample of South Asian interviewers, which may have resulted in bias in the reporting of alcohol consumption.

1.4.1.2 Awareness of risks.

Vora et al. (2000) studied a sample of South Asian men living in Leicester. They found that of all the migrant South Asian men sampled, Sikh men were least aware of the health risks associated with alcohol use. This study highlighted that migrant Sikh men were most vulnerable to alcohol related problems as they drank excessively and were not aware of the impact of alcohol on their health. The study used a quantitative design to assess alcohol, tobacco and paan¹ consumption in South Asian men. The authors highlighted differences in alcohol consumption between first and second-generation South Asian men. Whereby second generation south Asians were consuming more alcohol than first generation south Asians. However, they failed to explain these differences and did not provide any suggestions for clinical services or further research.

1.4.1.3 Religion.

Little emphasis had been paid in the literature to first-generation Muslim men as most reported abstinence from alcohol. The literature suggested the main reason for abstention in Muslims was that Islam prohibited the consumption of alcohol and thus explained the low alcohol consumption rates (Cochrane & Bal, 1990; Orford et al., 2004). However, within the literature a very small number of first-generation Muslim men had reported the consumption of alcohol (Cochrane & Bal, 1990; Vora et al., 2000). The authors who had highlighted these findings did not suggest reasons why a minority of first-generation Muslim men had consumed alcohol even though it was prohibited in this religion. Within the literature reviewed, no studies had explored the religious beliefs of alcohol use in first-generation South Asian men.

¹ Betel- quid chewing

Additionally, there may have been a reporting bias in Muslims due to the religious implications of reporting alcohol use and thus the data may be skewed (Subhra & Chauhan, 1999).

1.4.1.4 First generation alcohol use effect on second-generation alcohol use.

As noted above, migrant South Asian men consumed varying amounts of alcohol. The impact of their drinking on their UK born children had also been explored within the literature (Orford et al., 2004; Heim et al., 2004). The studies highlighted that UK born children's drinking habits may have been influenced by their parents' alcohol consumption beliefs.

Orford et al. (2004) reported that less than half of the Sikh and twenty percent of the Hindu participants reported that their fathers consumed alcohol. This was in contrast to only three percent of Muslim participants reporting that their fathers drank alcohol. The authors noted that across all South Asian groups, parental influence might have effected the consumption of alcohol in South Asian men, as participants who reported drinking were more likely to report parental alcohol consumption. This finding highlighted the potential influence of the parents acting as a role model for their children. Orford et al. (2004) found a high proportion of Sikh men and Hindu men were content with their parents knowing about their alcohol use. This was in contrast to a third of Muslim men who drank. Here they did not want their parents to know of their drinking. However, the authors did not provide any possible reasons for this finding.

The reciprocal role of the child's adherence to parent's behaviours was highlighted in another study. Heim et al. (2004) found that Pakistani men, who

abstained from alcohol use, reported that their abstinence had a positive impact on their relationship with their parents. Whereas Indian men reported that alcohol consumption did not have an impact on their relationship with their parents. The authors argued that intergenerational factors influenced alcohol consumption within second-generation South Asians. However, the Heim et al. (2004) study failed to investigate the differences between Hindu and Sikh participants, as this may have identified subtle differences between the religions. For example, Sikh parents may have been more accepting of alcohol consumption compared to Hindu parents, as Sikh fathers were more likely to drink than Hindu fathers (Orford et al., 2004).

There was limited research which examined the effects of alcohol consumption in first-generation South Asian men. Of the existing literature, none explored factors which affect alcohol consumption such as emotion regulation, influence of family and community. This may be because this sample of men may be less forthcoming to participate in research due to language barriers.

1.4.2 Second Generation South Asian Men

1.4.2.1 Acculturation and identity.

Second-generation South Asians were born in the UK or had migrated to the UK before the age of five years old and had significant exposure to the British culture (Orford et al., 2004). Literature in review highlighted the effects of acculturation on the second-generation South Asians. Acculturation is the “meeting of cultures and the resulting changes” (Sam & Berry, 2006, p1). In this review, it is referred to the convergence of the traditional attitudes towards non-consumption in South Asian culture and the liberal outlook in British culture.

In contrast to Cochrane and Bal (1990) more recent studies have highlighted that second-generation Sikh males drink comparable rates to Sikh migrant men and that some second-generation Muslim men have reported drinking more than migrant Muslim men (Bradby & Williams, 2004; Orford et al., 2004; Vora et al., 2000). Two studies which specifically studied the effects of identity and acculturation found that Sikh and Hindu men born in the UK were most likely to report consumption in line with White British counterparts, however Muslim men (Pakistani or Bangladeshi) mostly reported abstinence (Orford et al., 2004; Bradby & Williams, 2006).

Orford et al. (2004) specifically studied second-generation alcohol consumption and gathered quantitative data by interviewer-administered questionnaire method. The authors suggested that South Asian men who developed an integrated identity and acculturation style were likely to consume more alcohol. This was the case for second-generation Indian (Sikh and Hindu) males, as they were most likely to report their identity as British and Indian. This was in contrast to Pakistani and Bangladeshi (Muslim) men who were most likely to describe themselves as using their own ethnic identity label and were more likely to abstain from alcohol use. The study was one of the first to investigate the influence of acculturation and alcohol consumption in both Asian and Black communities. One limitation of this study is that the authors did not explain why differences in acculturation styles may exist between the groups. Further, they did not explain why second generation Sikh men were drinking comparable rates to migrant Sikh men. Bradby (2007) suggested that consumption of alcohol is part of Sikh culture and the increase of alcohol consumption may not be directly related to acculturation to British culture. Additionally, the researchers used religion for some analyses and country of origin for others (e.g. Hindu, Sikh, Pakistani and Bengali). This

highlighted the complicated nature of attempting to measure ethnicity as within South Asian communities religion and country of origin are intertwined.

Bradby and Williams (2006) investigated alcohol consumption in young South Asian men aged 18-20 years, who were followed-up from the age of 14-15 years. The authors reported an increase in alcohol consumption within Hindu, Sikh and Muslim religious groups during adolescent to adulthood transition. The largest increase was found within Hindus and Sikh men. The authors argued that Hindu and Sikh young men were less influenced by religion and culture at age 18-20 years compared to when aged 14-15 years. Religion significantly influenced young Muslim men to abstain from alcohol throughout adolescence to adulthood. Bradby and Williams (2006) suggested that the Punjabi culture protected the young adolescents from alcohol use. The Punjabi culture discouraged children from consuming alcohol and this came from the parents. However, the influence of Punjabi culture may not be strong enough for Hindu and Sikh men to be protected from alcohol use when parental influence is weakened. They suggested that strong religious prohibitions protected the Muslim men from alcohol use. The study highlighted that religion and culture played an important role in alcohol use choices made by young British South Asian men. The study did not factor in the influence of the acceptance of alcohol consumption as part of Sikh/Punjabi culture as this has been suggested to be a influencing factor for alcohol consumption in Sikh/Punjabi men (Cochrane & Bal., 1990; Bradby, 2007). However, they seem to have varying influences on the sub groups. The authors did not suggest reasons for an increase in alcohol use in Muslim men. Again, underreporting of alcohol consumption within Muslims may be explained by the religious prohibition of alcohol use (Subhra & Chauhan, 1999).

The literature on acculturation in second-generation South Asian men to date suggested that Hindus and Sikhs were most likely to adopt both their own ethnic identity and incorporate a British identity (Orford et al., 2004). A sample of second-generation Sikh Punjabi men seeking treatment for alcohol problems was noted to adopt a marginal acculturation style (Dhillon and Ubhi, 2003). This meant that the Sikh men did not identify with being Sikh or British. Dhillon and Ubhi (2003) used a qualitative approach to investigate the factors which may have influenced this acculturative state. They reported that second-generation Sikh men had negative experiences associated with living in Britain such as racism, and hostility from their own ethnic/religious group. The authors argued that participants' experience of not forming a clear identity might have contributed to the individual using substances such as alcohol to cope with this psychological tension. The study provided a potential factor for excessive alcohol use in Sikh men and offered implications for therapists working with this group. A limitation of the research was that the sample was restricted to second-generation Sikh men only and the authors failed to highlight limitations of this.

1.4.2.2 Emotion regulation.

Brar and Moneta (2009) and Spada and Moneta (2004) provided evidence which contradicts the suggestion that British Asians used alcohol to cope with negative emotions. Both studies examined the possible correlation between negative emotion regulation and alcohol use. Measuring symptoms of anxiety and depression, they found Asian students did not use alcohol to help moderate their negative emotions. Here South Asian students consumed similar rates of alcohol as White British students. The sample used in the Spada and Moneta (2004) study incorporated all Asian subgroups, which may have included a sample of Asians who

abstained from alcohol. Brar and Moneta (2009) only included Asians who were likely to drink, (students originating from India). This study failed to report and explore if some Indians included in the sample were Muslim, as many Muslims report originating from India. Another weakness of the study was that the authors did not consider the religious orientation of the Indian sample, which may have skewed the results, as Sikh men have been noted to drink more than Hindu men (Cochrane & Bal, 1999; Orford et al., 2004, Vora et al., 2000). The sample in these studies were undergraduate students and they may have been consuming excessive amounts of alcohol as part of the British student identity as identified by Spada and Moneta (2004). This would also influence how these results are interpreted.

1.4.2.3 Masculinity.

De Visser and Orford (2007) investigated the impact of masculinity and alcohol consumption by interviewing young men from diverse backgrounds. This sample was recruited from the community. They reported that second-generation South Asian men who consumed alcohol were more likely to endorse the belief that alcohol consumption was associated with being masculine. However, South Asian men who abstained, in particular Muslim men, were more likely to question the role of masculinity when related to alcohol consumption. For instance, these Muslim men offered alternative masculine traits such as being independent and choosing to be rational, which may be considered at odds with alcohol use. A limitation of this study was that it could only generalise its findings to second-generation Asian men. Bradby (2007) also found that masculinity was associated with alcohol consumption amongst non-Muslim men. This seemed particularly pertinent at celebrations such as weddings. For example, if a man was not seen to be participating in the drinking, his masculinity would be questioned. Additionally, Ahuja et al. (2003) argued that first-

generation Sikh men had come from a culture where the men's authority and alcohol consumption was associated with their masculinity.

1.4.3 Impact of religion on second-generation South Asian men

Religion was a further influencing factor, with Hinduism, Sikhism and Islam being reported to prohibit the use of alcohol (Bradby, 2007; Bradby & Williams, 2006; Cochrane & Bal, 1990; Heim et al., 2004; Morjaria & Orford, 2004; Morjaria-Keval, 2006; Orford et al., 2004:). Studies have shown that belief in religious adherence influenced the levels of alcohol consumed across the religions (Bradby, 2007; Bradby & Williams, 2006; Cochrane & Bal, 1990; Heim et al., 2004; Orford et al., 2004). Additionally, studies have reported that religion and spirituality have been strong factors to help with recovery from alcohol problems (Cameron et al., 2002; Morjaria & Orford, 2004; Morjaria-Keval, 2006).

1.4.3.1 Muslim Men.

Bradby and Williams (2006) reported that religion was a key factor for abstinence during youth to adult transition years, for Muslim men. They found a large percentage of Muslim men reported abstinence from alcohol because of religion. The authors argued that Islamic prohibition on consumption of alcohol was salient throughout adolescence to adult transition. This was further supported by Orford et al. (2004), who found that close identification to religion was linked to non-consumption of alcohol in Muslim adults. This was particular to Muslim men who identified with their religion (only 7% of the group who stated they were drinkers). Heim et al. (2004) explored the degree of religious adherence and its effect on alcohol consumption. When they analysed the importance of religion and whether participants practised religion, they found no significant differences in

alcohol consumption between abstinent and non-abstinent Muslim men. This finding contradicted earlier suggestions and the author failed to provide any explanations for this finding.

1.4.3.2 Sikh and Hindu Men.

Orford et al. (2004) found the amount of alcohol consumed was dependent on how closely men identified with their religion. For example, of Sikh men who reported strong religious identification, only 60% consumed alcohol. Whereas 94% of Sikh men who reported alcohol consumption, had identified weak religious adherence. The authors found that weak identification with religion was also associated with high reporting of problem drinking signs. Heim et al. (2004) also found that high ratings of religious importance in Sikh and Hindu men, was related to lower alcohol consumption in all South Asian men sampled. Bradby (2007) further illustrated this as Sikh men reported admiring baptised Sikh men for their religious devotion and strength to abstain from alcohol consumption.

The literature on religion highlighted that strength of religious adherence was related to alcohol consumption. Within the Sikh community, it was noted to be a choice of committing to the religion, whereas in Islam, alcohol consumption was forbidden and most Muslim men adhered to this. These findings suggested the notion that religious adherence within South Asian religions may protect some men from alcohol use. The above studies had supported that strong religious identity and adherence was a protective factor for South Asian men.

1.4.3.3 Religion and Recovery.

A few studies have reported that religion was used to help recovery from alcohol problems (Cameron et al., 2002; Morjaria-Keval, 2006; Morjaria & Orford,

2002). It was found that, as well as being a protective factor from alcohol use, religious belief and attitudes also served as a treatment factor for alcohol problems. These findings were not based on a thorough search of the literature and were based on the literature identified through the search.

Morjaria and Orford (2002) explored the experiences of South Asian men who used religion and spirituality in their recovery from excessive alcohol use. They found that South Asian men who had an established faith would seek to draw upon their embedded cultural values when they need help. The values included belief in God and the role of 'karma', which is when "all things are pre-destined and are as a result of past life/lives actions" (Morjaria & Orford, 2002 p.44). By engaging in these values, the men described an active stage of praying and attending the temple. These phases encouraged the men to re-engage and reaffirm with their 'dormant' religious beliefs. The South Asian men reported themes of pride and fear. These themes were perceived positively as they encouraged good adherence to religion. The South Asian men aimed for controlled drinking and reported that recovery was a continual process. The authors suggested that South Asians viewed their alcoholism as a trigger to re-evaluate their lives and adjust psychologically using a holistic perspective. The study added positive contributions to the field of alcohol recovery, as it addressed and contrasted the facilitation of 'natural' recovery in South Asian religions with standard treatment. Although the study produced interesting findings, the research methodology was not explicit, in that there was limited detail regarding recruitment information and the authors did not include whether the participants were first or second-generation South Asians. Exploring the difference in generation and level of acculturation, may have provided better insight into whether differences exist between the recovery of first and second-generation South Asian men. Further,

the authors combined the religious experience of Sikh and Hindu men and failed to highlight the differences between the religious elements.

In order to investigate in detail the role of religion during recovery from alcohol problems in South Asian men, Morjaria-Keval (2006) studied the religious and spiritual coping mechanisms involved in change among ten Sikh heavy drinkers. These men had reduced or abstained from alcohol for at least a period of four months. The author proposed a model of change for the process of recovery for Sikh men. A 'cognitive reappraisal' of the Sikh men's drinking was triggered by a significant life event or experience. Morjaria- Keval (2006) added that a phase to commit to change involved re-establishing supportive links with religious networks. Some men had taken vows or had become baptised Sikhs. The authors suggested that the emotional and physical engagement in the temple allowed the Sikh men to divert social time in contexts that did not encourage alcohol consumption. This study provided additional support to the body of evidence which suggests participation in religious activities helped South Asian men to recover from alcohol misuse. A weakness of the study was that authors failed to highlight the importance of family and social networks and its role in the recovery from alcohol problems.

1.4.3.4 Social support in recovery.

Two studies in the literature highlighted the importance of social support for South Asian men with alcohol problems (Ahuja et al., 2003; Cameron et al., 2002). Ahuja et al. (2003) found that wives initially attempted to control the drinking behaviours of their Sikh husbands'. This often failed with women reportedly becoming emotionally detached and partially independent from their husbands. Despite the emotional detachment of the wives, the women continued to abide by

their traditional duties and tolerated their husband's drinking. Ahuja et al. (2003) interviewed the Sikh husbands and found that most of the men were unlikely to report that their drinking was problematic. Some men acknowledged excessive alcohol consumption and these men suggested that excessive alcohol consumption was encouraged by their culture (e.g. drinking excessively at weddings and parties). The author highlighted that the Sikh men negatively perceived their wives' changes in attitude to them. They suggested that the assertive behaviour of the wives threatened the masculine identities of the Sikh men. This study provided positive contributions to the literature as it described detailed insight to the effects caused by Sikh men's drinking on the family. A weakness of the article was that the authors failed to highlight the impact of the role of the tolerant wives on their husbands' drinking behaviours. This study highlighted that cultural sensitivity may be required when working with first-generation Sikh men. It also supported the involvement of the wives in the treatment process for Sikh men with alcohol problems.

Cameron et al. (2002) studied a sample of men who recovered from alcohol problems without the aid of treatment services. The authors reported that both South Asian and White British men stated similar motivating factors which helped to alter their problematic alcohol consumption e.g. negative impact on physical health and self esteem. However, South Asian men were more likely to state that alcohol negatively affected their social networks, their family status and honour. As a result, these factors modified their alcohol consumption. Morjaria-Keval (2006) also reported that Sikh men re-assessed the impact of alcohol on aspects of their life e.g. their family and social standing within the community. Cameron et al. (2002) reported that South Asian men felt a deep sense of pride about their position in the community and feared it would be tarnished if they did not tackle their alcohol

problems. The authors identified that South Asian men had spontaneously reduced their alcohol consumption without the aid of standard treatment services and the study highlighted the potential reasons for this. A weakness of the study was that data analysis was not clear, as no rigorous method of analysis was reported. Additionally, the authors noted an overrepresentation of Sikhs in comparison to the local population. They suggested that some influencing factors may have been because of one of the interviewers being Sikh; Sikhs have been more likely to have alcohol problems; or that Sikhs were more forthcoming about alcohol issues. The South Asian sample also included a mixture of mainly first and some second-generation men and did not report any differences between the generations.

1.4.4 Treatment seeking barriers

1.4.4.1 Awareness of services.

The studies found little difference in treatment seeking sources between South Asian groups (Heim et al., 2004; Orford et al., 2004). Sources identified by the literature ranged from General Practitioner (GP), health centre, friends and internet (Heim et al., 2004; Orford et al., 2004). Many South Asian men did not identify community leaders as appropriate sources of support for alcohol problems (Orford et al., 2004). Whereas Heim et al. (2004) highlighted that some young Pakistani men did suggest involving the mosque for community support. Within the literature many South Asian men did not know of any specialist alcohol services, apart from a small number of second-generation Bangladeshi men who suggested Alcoholics Anonymous (Orford et al., 2004). This finding emphasised the potential difficulties South Asian men faced when attempting to access support for alcohol problems. There seems to be a limited awareness of specialist service support and young South

Asian men did not feel their own communities were a source of support. The research which investigated these factors had mainly sampled second-generation South Asians. There was limited evidence of service awareness in first-generation South Asian migrants and thus little is known about where they would access support apart from religious community support (Morjaria & Orford, 2004; Morjaria-Keval, 2006).

1.4.4.2 Stigma.

Another barrier faced by South Asian men was the impact of the stigma of having an alcohol problem (Cochrane & Bal, 1990; Heim et al., 2004; Orford et al., 2004; Cameron et al., 2002). Some differences between how different South Asian communities dealt with alcohol problems were noted. For example, Heim et al. (2004) reported that young Pakistani men did not feel their community dealt with alcohol problems in the same way as the White population. They reported that their community hid, or ignored the alcohol problem. Heim et al. (2004) argued that young Pakistani men respected the dominant value of non-consumption of alcohol. It was noted that they were aware that the older generation did not or were not willing to recognise the problem existed within their community. The authors described this as ‘generational dislocation’ between the young and older generations. The authors highlighted that Pakistani men stated that use of ‘violence’ or being ‘sent back to Pakistan’ were forms of dealing with alcohol problems. These findings suggested that Pakistani communities did not accept alcohol problems thus suggesting intolerance to alcohol consumption based on their religious beliefs. Pakistani men may therefore become uncomfortable disclosing alcohol use to their community and may suffer in isolation with alcohol related problems as highlighted by Heim et al. (2004).

Sikh men have been found to be less likely to ask for help (Orford et al. 2004), and have been reported to be less likely to recognise their own drinking problems (Ahuja et al., 2003; Orford et al., 2004). Further, they were found to not identify with labels associated to requiring support e.g. 'addict' (Cameron et al., 2002). Heim et al (2004) suggested this could be because their communities may not be as understanding of the problems associated with alcohol use.

1.5 Discussion

1.5.1 Summary of findings

The aim of this review was to analyse the existing literature on South Asian men and alcohol use. The review highlighted a number of related factors which affect South Asian men's alcohol consumption. These factors are complex, for example, there is a consensus that within South Asian communities there is a religious and cultural intolerance to alcohol consumption. However, this is contradicted by reports of heavy alcohol use within specific South Asian group's (e.g. Sikh and Muslim men).

The article reviewed the limited literature on migrant South Asian men and found that consuming alcohol was part of social culture in parts of India for Sikh men. However, the informal contexts where drinking takes place had possibly affected the way migrant Sikh men had consumed alcohol for example; they used informal alcohol unit measures. Therefore, Sikh men may be vulnerable to risky alcohol consumption practices, as they were least aware of the health risks associated with excessive alcohol consumption. In contrast to this, migrant Muslim men were abstinent from alcohol and reported that prohibition within Islamic law influenced their alcohol consumption.

The influence of first-generation parents was also an important factor for alcohol consumption in second-generation South Asian men, as the literature highlighted that South Asian men were influenced by their parents' attitudes to alcohol consumption.

It was noted that second-generation non-Muslim men were more likely to adopt an acculturative identity, whereby both ethnic and British cultural identities were incorporated. This factor influenced the consumption of alcohol and was not found in second-generation Muslim men, as they used their own ethnic label to describe their identity. It could be suggested however, that second-generation Muslims who were reporting alcohol consumption may have been attempting to 'fit in' with the British culture, and this conflicted with their religious and cultural identity. Second generation Muslim men may experience feeling alienated from British society, as their religion strictly prohibits them to consume alcohol. However, in attempting to adopt British cultural customs such as drinking alcohol in a pub, may result in 'culture conflict', which includes feelings such as guilt. This psychological tension has been found and reported in literature. Here, South Asian females living in the UK, experienced a personal conflict between liberated Western (British) and Eastern rigid (Islamic/Asian) values (Burr, 2002 p. 840).

The review also highlighted that South Asian students did not consume alcohol to regulate anxiety and depression. However, using a student sample may not be appropriate to generalise across all South Asian communities, as heavy alcohol consumption may be part of the student lifestyle and identity.

An additional identity factor of masculinity was explored in the literature. It was reported that alcohol consumption is linked to a masculine identity and this view

was supported by South Asian men who consumed alcohol. Muslim men were more likely to endorse this idea focussing on alternative masculine traits such as independence and being rational.

The impact of religion was an influencing factor for some second-generation South Asian men. Young Muslim men generally adhered to their religious prohibition of alcohol use and this had remained in the majority of second-generation Muslim men. Only a minority of Muslim men reported heavy alcohol use and this could be explained by the influence of acculturation. Religious adherence was also an influencing factor for alcohol consumption within Sikh and Hindu men. This was supported by studies which highlighted the utility of religion as an aid to recovery from alcohol problems. However, it could be argued that both religious affirmation and support from social networks may have contributed in the recovery for the men sampled in the studies. This suggestion draws parallels with standardised treatment, as the combination of social support and cognitive reappraisal are also included in formal standardised treatment. The literature highlighted that disintegration of social networks caused by problematic alcohol use influenced South Asian men to modify their consumption. It could be suggested that first-generation men were more likely to be influenced by social supports and family honour compared to second-generation men who may be more acculturated to the British culture. Thus, the second-generation may have reported similar reasons for abstinence as the White British sample.

Barriers to seeking treatment for alcohol problems were also discussed in the literature and it emerged that many South Asian men were not aware of specific support services. Some South Asians suggested they could contact their religious

networks, however most did not feel that religious and community leaders were supportive. Additionally, stigma was reported to be a contributing factor to the barrier of seeking treatment for alcohol use in South Asian communities, whereby older migrant generations were unwilling to recognise the existence of problems within their communities. This may in turn result in the individual having to cope in isolation and suffer further as this group have a limited awareness of how to access appropriate services (Rao, 2006).

The current review has discovered differences between religious groups and generations of South Asian men. The rates of alcohol consumption are increasing within South Asian communities. This increase in consumption will have implications for health services as South Asians are predisposed to a genetic vulnerability to alcohol damage (Pannu et al., 2009). Additionally, the effect of acculturation may influence South Asian communities, as cultural and religious traditions appear to be weakening in the protection against alcohol use.

1.5.2 Limitations

The majority of the studies reviewed included dominant South Asian communities residing in the UK. However, many of the studies solely focused on problematic alcohol consumers, which tended to be reported by Sikh men. As the literature implied, this may be due to a higher number of Sikh men having alcohol problems or that they are less constrained in reporting their alcohol problems. Limited attention has been paid to the minority of Muslim men who reported consuming excessive amounts of alcohol. This may be due to reluctance of reporting issues due to religious prohibitions and stigma within the Islamic communities.

Many of the studies were additionally limited as they did not seek differences between first and second-generation South Asian men and no studies reported the attitudes and beliefs of alcohol consumption within first-generation South Asian men. Bhopal, Vettini, Hunt, Wiebe, Hanna, and Amos (2004) reviewed the adequacy of survey measures used to assess alcohol and tobacco use within ethnic minority communities. They found discrepancies in prevalence rates between localised studies. However, despite finding overall inconsistencies, they found that national studies were consistent for South Asian men reporting alcohol consumption.

Bhopal et al. (2004) argue that despite an emerging evidence base within ethnic minority alcohol and substance use, results should be used with caution. This is because majority of the research conducted was based on survey data and validity of this data may be vulnerable to reporting biases. Additionally, the section on religion and recovery emerged from the literature from the original search and was not based on a thorough search on the topic. Therefore, this particular section may not include all relevant information on this topic. Some studies in the review used quantitative methodologies to gather data, these studies captured large amounts of information however, and they did not explore possible reasons why the behaviour occurred. The large quantities of data reported in the studies made it very difficult to synthesise the findings with other research and the use of different labels to describe the South Asian groups added to this challenge. Due to the nature of quantitative analysis, it was difficult to ascertain substantial evidence for specific South Asian male groups, as the numbers of the groups were very limited. The qualitative research provided in-depth data on specific sub-groups of the South Asian community although some groups (e.g. Muslim men, first-generation South Asian

men) were often not investigated. Taking into account the limitations of the literature reviewed, findings of the review should be considered with caution.

1.5.3 Implications for practice

The main factor to be considered within clinical services which support South Asian men with alcohol issues is the need to regard the impact of acculturation. This is pertinent as first-generation South Asian men may hold traditional attitudes and beliefs about alcohol use. Whereas second-generation South Asian men may face conflict to manage contrasting cultures. Additionally, the exploration of religious beliefs and attitudes towards alcohol consumption and the links with religion may be important. Elements of spirituality and religiosity may aid South Asian men in the recovery from alcohol problems. Morjaria-Keval (2006) suggested that using the elements of religion and culture may be appropriate to inform of treatment of specific ethnic minority groups. This may include utilising a person-centered approach to incorporate spiritual and religious elements within the assessment process, which is often neglected (Dhillon & Ubhi, 2003; Morjaria-Keval, 2006). The literature addressed the importance of social, community and family support networks and how these should be considered as influencing factors. Strong community, family and social networks may protect South Asian men from consuming alcohol and may provide support with recovery from alcohol problems.

Ahuja et al. (2003) suggested inclusion of the family may be important when considering working with Sikh men with alcohol use problems. Support from wives may help promote change within the husbands. Services may also think about supporting wives and other family members who may feel distressed by the South Asian men's excessive drinking. In addition to this, Dhillon and Ubhi (2003)

highlighted that the participants found difficulties in accessing therapy. The referral sources mainly came from secondary care, close friends, or family members. The authors stated that South Asians were unable to understand how therapy would help with their problem and lacked trust in White therapists as they felt the therapists would not understand Asian culture and problems. Therefore, the literature had suggested clinicians needed to be mindful and sensitive towards the beliefs and attitudes towards clinical services.

Exploration of creating ethnic specific services for alcohol users was considered and welcomed by most South Asians (Heim et al, 2004). However, they also reported that 32% of Indian and 5% of Pakistani respondents believed that their communities should not be treated differently. Rao (2006) highlighted that service providers may be resistant to develop treatment services that are ethnically sensitive, for fearing being seen as racist. Additionally, they may also be concerned that communities would not engage in specialist services. Despite this, it is evident that positive changes in services have occurred over the past ten years and ethnic minorities may be accessing specialist services through generic mental health services (Rao, 2006). A possible consideration is to employ more ethnically diverse staff who have acquired language skills and cultural knowledge. The literature highlighted that some participants had fears about South Asian therapists, in that they would disclose their problems to community (Dhillon & Ubhi, 2003). Therefore, consideration and sensitivity needs to be placed on providing choice of therapist.

1.5.4 Implications for future research

There is a lack of literature which explores the psychological and social factors of alcohol use in South Asian men. It is recommended that further research is warranted. In particular, studies should aim to explore the influence of culture, role of identity, awareness of risks, religious attitudes and beliefs in first-generation men using both qualitative and quantitative methodologies. Further research could investigate the experiences of first-generation South Asian men migrating to and living in the UK, to explore whether challenges to their identity and acculturation had an impact on their alcohol consumption, as this was highlighted in second-generation men by Dhillon and Ubhi (2003).

It is important to note that although Muslim men may have been protected from alcohol use by their religion to an extent, they may also have experienced difficulties living in the UK and it would be interesting to explore what alternative coping strategies they may use when faced with such psychosocial adversity. Research could also investigate the experiences of second-generation Muslim men who report heavy drinking to help inform services how to engage and support this minority group. More understanding into the different cultures and religions is needed. Additionally, the inclusion of research with South Asian communities and staff who work with alcohol problems is required. Health education needs to be put into place at an early stage using religious and cultural factors, which South Asians could better identify with. Collaboration with researchers and clinicians is needed to convey and devise appropriate health messages to the South Asian communities.

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Chapter Two: An Exploration of South Asian Women's Psychological Cancer Treatment: An Interpretative Phenomenological Analysis

Word count (excluding title, tables and quotes): 7,728

Article prepared for submission to the Journal of Psychosocial Oncology (See appendix 2 for notes to contributors)

2.1 Abstract

The study investigated the experiences of British South Asian women who accessed psychological treatment within a cancer service. Four South Asian participants were recruited and took part in in-depth semi-structured interviews. Six key informants participated in focus groups to provide staff perspectives. Interpretative Phenomenological Analysis elicited themes of pre-existing beliefs, psychological journey of cancer treatment, and impact on family, friends and generations. Key informants highlighted that South Asian patients and staff faced challenges as a theme. The research findings address that better education and awareness for South Asian communities and staff is necessary. Methodological limitations of this research are highlighted.

Keywords: South Asian women, cancer, psychosocial experience, qualitative

2.2 Introduction

The South Asian community currently accounts for 3.9% of the British population making it the largest ethnic minority category (Office for National Statistics [ONS], 2001). Individuals who identify their country of origin as India represent over half of the South Asian group, followed by Pakistan and Bangladesh (ONS, 2001). Between 2002 and 2006, approximately 6,685 South Asians were reported to have been diagnosed with cancer in England (The National Cancer Intelligence Network & Cancer Research UK, 2009). The research highlighted that Asian groups were significantly at lower risk of developing cancer compared to the White population. This finding was common to all Black and Minority Ethnic (BME) groups. Despite the lower prevalence and risks for developing cancer, variations associated with cancer incidence exist within the South Asian groups (Redman, Higginbottom, & Massey, 2008).

There is disparity between the experiences of cancer treatment between BME and White patients and this inequality was addressed in the Cancer Reform Strategy (Department of Health, 2007). Elkan et al. (2007) reviewed the literature on the experiences of BME groups that accessed cancer services. The authors reported a number of barriers for BME patients including lack of awareness of services, difficulties with language barriers, and beliefs about cancer and health. Additionally, the review highlighted that service providers had limited awareness of BME cultural issues. The BME patients highlighted that service providers did not consider their religion or gender issues, and that some staff attitudes were perceived as racist. It is recognised that psychological distress is common amongst cancer patients (Department of Health, 2000). The treatment of psychological distress is warranted

as it may affect clinical treatment outcome. It can also have a negative impact on quality of the patient's life (White & Macleod, 2002).

The Cancer Reform Strategy (Department of Health, 2007) suggested that improvement of overall cancer treatment for BME groups should include better advice, information, support and more psychological help for cancer survivors and those living with cancer. The Cancer Plan (Department of Health, 2000) recommended offering psychological treatment as an essential component to cancer treatment.

The literature which explores the psychological and social experiences of South Asian cancer patients is limited. With regards to accessing services, Indian, Pakistani and Bangladeshi women were more likely to report emotional barriers to seeking help e.g. embarrassment and fear of what a doctor may find (Waller, Robb, Stubbings, Ramirez, Macleod, Austoker et al., 2009). Roy, Symonds, Kumar, Mitchell, and Fallowfield (2005) found Asian cancer patients were more likely to catastrophise their cancer diagnosis and scored higher on hopelessness/helplessness scores. The authors reported Asians were more likely to disbelieve they had cancer and that denial was linked to a lack of 'fighting spirit'. A study that investigated the experiences of cancer from a sample of Canadian South Asian women reported that the women turned to religion and spirituality to help them make sense of their illness and religion provided a source of support (Gurm, Stephen, MacKenzi, Doll, Barroetavena & Cadell, 2008). The authors argued that variation between first and second-generation South Asian women might be an impact of acculturation.

In summary, the current literature indicated inequality of access to psychosocial cancer treatment for South Asian cancer patients, with several barriers

in accessing services. Although positive steps have been made to address these issues, there is currently a lack of research which explores how the South Asian population access and experience psychological therapy within the context of cancer services. The current research aimed to address the existing gaps in the literature by exploring the in-depth experiences of South Asian cancer patients of psychological treatment. Key informant perspectives are also explored.

2.3 Method

2.3.1 Design

A qualitative design methodology was chosen because this approach sensitively explored the topics appropriately. It also was used because it enabled participants who were often faced with barriers in engaging services, to share their views and experiences.

2.3.2 Participants

Basic demographic details of the South Asian participants were sought and are presented below (see table. 1). The study attempted to recruit a sample of South Asian participants; however, no male South Asian participants volunteered to take part in the study. Additionally, one female was recruited and interviewed. This participant's data was excluded from the analysis as she was a carer for a cancer patient and a homogenous sample is preferred for Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009). Therefore, four South Asian women's interview data was included for analysis. The South Asian women's age ranged from 46 – 62 years (mean 51.5 years). Three South Asian participants described their country of origin as India and one stated Pakistan and India as her countries of origin. Three out of the four women stated they practised religions, to include Hinduism, Islam, and

Sikhism. One woman stated that she currently did not follow a religion. Three of the four participants had a diagnosis of breast cancer, and one a diagnosis of Leukaemia. Two women were born in the UK and two women migrated to the UK forty-four years ago from India and East Africa. All South Asian participants spoke English and spoke additional languages including Punjabi, Gujarati, Urdu and Mirpuri. The sample was deemed suitable for IPA analysis as “participants are selected on the basis that they can grant us access to a particular perspective on the phenomena under study (Smith et al., 2009, page 49). Therefore, the participants who volunteered to take part in the study were able to provide their perspectives of being ‘women’ who identify as having ‘South Asian culture’ and have ‘experienced psychological treatment’ for their ‘cancer illness’.

Table 1. Demographic details of South Asian participants

Participant name²	Country of origin	Religion	Country of Birth	Languages spoken	Lived in UK	Diagnosis
Navpreet	India	None	UK	English, Punjabi	Since birth	Breast Cancer
Indumati	India	Hindu	India	English, Gujarati,	44 years	Breast Cancer
Saadia	India and Pakistan	Muslim	Africa	English, Punjabi, Urdu, Mirpuri	44 years	Breast Cancer
Sharanjeet	India	Sikh	UK	English, Punjabi	Since birth	Leukaemia

² pseudonym used to preserve anonymity

The study also recruited six key informants to participate in the research (see table 2). The roles of the key informants varied within the first focus group and included a specialist Counsellor, Community Worker and a Chaplain. Within the second focus group all of the key informants were clinical nurse specialists. Four key informants described their ethnicity as White, two of the key informants were Asian, and all of the key informants were women.

Table 2. Details of key informants

Focus group	Key informant (K) number	Key informant profession	Ethnicity
One	K1	Specialist Counsellor	White
	K2	Community Worker	South Asian
	K3	Chaplain	South Asian
Two	K4	Clinical Nurse Specialist	White
	K5	Clinical Nurse Specialist	White
	K6	Clinical Nurse Specialist	White

2.3.3 Measures

2.3.3.1 In-depth interviews.

The study used semi-structured interviews to gather in-depth data from South Asian participants. The use of semi-structured interviews enables flexibility, as they are more suited to exploring an individual's response to the research question (Fylan, 2005). The semi-structured interview is a versatile method as contradictions within accounts can be explored. Further, they are ideal for discussing sensitive topics (Fylan, 2005). This method of data collection was also selected to accommodate potential discomfort with talking about experiences within a group setting. It also facilitates the elaboration of responses. An interview schedule (appendix 10) was developed to facilitate discussion. The interview schedule consisted of open-ended questions which aimed to capture demographic details, explored participants experiences of psychology services and their perceptions of South Asian community access to psychology within a cancer context. The interview schedule was piloted during the first interview and data was included in the final analysis. Although

participants were asked for feedback regarding the interview schedule, no changes were recommended.

2.3.3.2 Focus groups.

Focus groups were used to gather in-depth information from key informants from experiences of South Asian cancer patients. The key informants often met as groups for multidisciplinary team meetings and therefore focus groups were considered a naturalistic method of data collection. Additionally, Tomkins and Eatough (2010) argued that focus groups allow reflection on themes and experiences in an interactive environment.

A focus group schedule (appendix 11) was developed and consisted of questions encompassing the key informants' experiences of working with South Asians, including; beliefs about the support obtained and barriers to services.

2.3.4 Procedure

Ethical approval was sought and obtained by Coventry University ethics committee (appendix 4), the local National Health Service Trust Research Ethics committee (appendix 5) and local Research and Development service (appendix 6). The study recruited South Asian patients who had accessed treatment from the clinical psychology service within an oncology and palliative care service. The definition of South Asian referred broadly to people whose familial or cultural backgrounds originated from the subcontinent of India, Pakistan and Bangladesh (Marshall & Yazdani, 2000). South Asian participants were only included if they identified their ethnicity under the broad term of South Asian, and had received assessment and/or treatment by the clinical psychology service. It was decided to exclude South Asian participants who had a terminal diagnosis, as their

psychological needs would have been markedly different to patients that were either living with cancer or were survivors of cancer (Gao, Bennett, Stark, Murray & Higginson, 2010). South Asian participants were identified from the psychology service active caseload and discharge list. Information letters (appendix 7) about the study's aims and procedure were sent to potential participants with a copy of the consent form (appendix 9). Interested participants were advised to contact the lead researcher. At the interview, South Asian participants were provided an opportunity to ask any questions relating to the study and they were reminded that they could withdraw from the study at any point. Once queries about the study were addressed, written consent was sought and interviews were conducted at the participant's home or within the health service. The interview duration ranged from forty to ninety minutes. On completion of interview, the lead researcher debriefed the participant and provided a summary of the session content and this process allowed for validity checking of the data.

The key informants were multidisciplinary professionals recruited from a cancer service based in a health service in the West Midlands. The main inclusion criteria for key informants, was that they provided a service within cancer services. The lead researcher recruited key informants through giving presentations on the study to multidisciplinary meetings. Information was also distributed through information letters (appendix 8) and consent forms (appendix 9) were given out. Key informants interested in participating in the study contacted the lead researcher. At the focus group, key informants were provided an opportunity to ask any questions relating to the study with the researcher and were reminded that they could withdraw from the study at any point. Once all queries were answered, key informants provided written consent and focus group interviews commenced.

Two focus groups were held and consisted of three participants within each focus group. It was decided to conduct two focus groups to allow for better management of participant interactions and provide additional opportunity for staff to attend the focus group. The focus groups were conducted at a healthcare service site and lasted between thirty to fifty minutes. On completion of the focus groups, the lead researcher debriefed and provided a summary of the session content and this process allowed for validity checking of the data. The first focus group was considered as a pilot and feedback was sought from participants. No amendments were required. Data obtained from the pilot focus group was included in the final analysis.

All individual interviews and focus groups were audio recorded and transcribed verbatim. Pseudonyms or unique codes were used to replace personal identifiable information for protection of confidentiality. Participant's English language was variable within both individual interviews and focus groups and was amended by the researcher for grammatical sense indicated by brackets.

2.3.5 Analysis

The data was analysed using IPA (Smith, Flowers & Larkin, 2009). This particular approach was chosen because of its epistemological underpinnings of phenomenology, hermeneutics and idiography. The phenomenological position of this analytical approach aims to gather and understand 'lived experience'. This was appropriate for this study as the research was concerned with gaining an understanding of South Asian women's 'lived experience' of psychological therapy for their cancer treatment.

In order to gain an understanding of the participants experience the researcher is required to provide interpretations of the data, which is the theory of hermeneutics. Interpretation allows the researcher to make sense of how a phenomenon appears. Therefore, it was of the researcher's interest to understand how and why the South Asian women with cancer experienced psychological treatment. As the researcher used their own experiences and knowledge to make sense of the participants experience it was important to consider the researchers background position (Appendix 12) to help consider the influencing factors for interpretation.

Finally, IPA is concerned with idiography, which is the concern of the 'individual' experience. This is evident in the attention to detail of the experiences and depth of analysis. This was an important factor for choosing IPA also as, cancer treatment for the South Asian participants may be unique. The research aimed to capture the rich detail of the South Asian women's individual experience of psychological therapy within cancer treatment, as this has received limited attention in the UK literature. Further, the small sample size illustrates the concern for understanding how a group of people from a particular context have experienced an experiential phenomenon and the research aimed to highlight the divergence and convergence of experiences.

IPA aims to interpret how an individual makes sense of their "major life experiences" (Smith et al., 2009, p.1). This approach is well suited to investigate the experience of cancer treatment in South Asian women, as IPA takes into consideration the reflections of a major life event made by an individual.

Transcripts were read in depth a number of times to gain familiarity with the data. Reflective and descriptive comments were made and constructed into emergent themes. Comparisons between emergent themes were made to create theoretical connections. Emergent themes were clustered based on the connections and were developed into superordinate themes. The superordinate themes encapsulated the emergent theme concepts (detailed procedure can be found in appendix 12). As part of the analytic process it was important to consider the position of the researcher (appendix 12).

The focus group verbatim data was also analysed using an IPA method devised specifically to extract the idiographic experiences of the individuals from the focus groups (Palmer, Larkin, de Visser, & Fadden, 2010). This method included analysis of each individual's perspectives, roles and relationships between people and the themes of the stories described. Once the group dynamic patterns were taken into consideration, the emergent themes were integrated to develop superordinate themes for the focus group data (see appendix 14 for protocol used and appendix 15 for integration of focus group data). For both sets of analysis, an independent colleague and the supervisory team checked themes for consistency and validity.

2.4 Results

The individual in-depth interviews with the South Asian participants were analysed using IPA. Separate IPA analysis was conducted on the focus groups, as these groups were different samples.

2.4.1 Themes from individual in-depth interviews

Three superordinate themes emerged from the data analysis of the in-depth interviews with the South Asian participants. The first explored the beliefs that

participants held about mental health and psychology services, as well as the impact of mental health on the self. The second explored the psychological process of the cancer treatment journey. This included psychological experiences from diagnosis to the psychological treatment. The final theme highlighted the experiences and support from family and generational differences that existed (see appendix 16 for additional supporting quotes).

Table 3. Summary of themes for in-depth interviews

Superordinate Themes	Emergent theme
Pre-existing beliefs	Psychological and mental health services Mental health and self
Psychological journey of cancer	Diagnosis and treatment Meaning making Psychological therapy Strengths and hope
Family, friends and generations	Emotional effect on family Family is there for practical support Family is not there emotionally Generational differences

2.4.1.1 Pre-existing beliefs.

The South Asian participants articulated their perceptions about psychological treatment and mental health services prior to accessing them, and in doing so they described what it meant to them.

2.4.1.1.1 Psychological and mental health services.

When Navpreet talked about her beliefs associated to mental health services, she stated that they were unhelpful. She explained that her mother suffered with a mental health problem and said:

If they couldn't help my mum, how could they help me?

(Navpreet: lines 133-134)

Saadia was aware of psychology services, however had never accessed them until she was diagnosed with breast cancer:

I thought if she's Asian she's not going to know how I feel and with my family all being Asians they don't know what I'm going through. They can't... erm...so is she going to be? (Saadia: lines 108-111)

The referrer informed Saadia that the psychologist was Asian. However, Saadia did not initially feel comfortable with the idea that she would see an Asian psychologist, as she believed that they were unable to understand what it feels like to have cancer. Saadia explained that her assumption was derived from the fact that her family were not empathic to her experience of cancer. Hence, her perceptions of Asians lacking empathy had generalised to others.

It is read that South Asian women may have negative perceptions about mental health services and are less likely to access services.

2.4.1.1.2 Mental health and self.

The participants also expressed their perceived negative repercussions of accessing psychological treatment. In this excerpt, Navpreet highlighted the issue of stigma being attached to seeking mental health support:

I was thinking that I was normal and I'm in control. I didn't talk about it much to people. I knew I wasn't in control at the time but I wanted to be. I was scared to go to... I didn't want to be classed as... she's under the... psychologist... a psychopath, you know, I don't know why. You know mad person. I didn't want to be classed as that. I didn't want to go there. (Navpreet: lines 57-62)

The issue of stigma may be an additional barrier for participants accessing psychological treatment within a health context. Whereas Sharanjeet had previously accessed psychological treatment and had a positive outlook towards accessing services:

Well I was hoping she could help me, I wasn't thinking all negative and thought 'oh my god' there's something mentally wrong with me...because obviously going through what I did and having counselling before. (Sharanjeet: lines 48-50)

This example illustrated that despite having previously accessed psychological services Sharanjeet was still aware of the stigma attached with

psychological problems. This suggested that accessing services has a positive outcome as it may help to reduce stigma in South Asian communities.

2.4.1.2 Psychological consequences.

The participants spoke about a range of emotions and feelings that were associated with their ‘cancer treatment journey’. The emotions of participants varied depending on the stage of the cancer treatment process.

2.4.1.2.1 Diagnosis and treatment.

Participants described feelings of shock and despair that fuelled denial of diagnosis in some participants. Indumati described that the experience of receiving the cancer diagnosis was as if the cancer word had ‘stuck to her’ as she could not hear the comforting words of others. Indumati expressed her distress by stating she became very tearful and found it difficult to absorb anything else. She said:

But [in] my mind, in there is still [the] cancer word... I didn't take [in] anybody's [words], I [didn't] listen. They talk[ed] to me, they give me [a] lot of strength and everything...but in my mind is the cancer word... I [couldn't] think [of] anything [else]... I [kept] crying. (Indumati: lines 61-65)

It could be interpreted that the participants may have felt that their life was at risk and that death was imminent, a common traumatic response. After receiving a diagnosis of cancer, the participants spoke about how the following treatment was an overwhelming process. Saadia explained, “*it was one thing after another*” (Saadia: line 34). The participants had no prior knowledge of the treatment procedure or the possible psychological impact:

I didn’t know what to expect to be honest with you and when you are grieving, as I was grieving... just like losing an arm or your leg, you know losing your breast. I didn’t expect anything.
(Navpreet: lines 182-185)

Navpreet used the word ‘grieving’ to illustrate what she felt when her breast was removed. She also further emphasised the loss by stating that losing her breast was equivalent to losing a limb.

Analysis of the interviews revealed that some participants were not aware of the emotional and psychological effects of cancer. Navpreet described:

...I didn’t know what it was at the time. As far as I was concerned, I was going to have the operation and get back to work. I didn’t realise the trauma that I was going to go through.
(Navpreet: lines 660-662)

Again the experience of the treatment was described as ‘traumatic’, illustrating the power of the emotional impact of cancer. Indumati also echoed the point made by Navpreet previously of the feelings of grief at losing her breast. However, Indumati also stated that the operation was a bittersweet experience:

After that, I was relieved, but I felt like I had lost one of those parts. I [had] lost it. Afterwards it was just shock, the chemotherapy, radiotherapy. They [gave] me all [of the] leaflets, video, everything and books I [could] read. The more I read [them] the more I [got] frighten[ed]. I [became] really frighten[ed]. (Indumati: lines 111-115)

Indumati described that after the relief and grief of the operation, further emotions of shock and fear followed. These additional feelings may cause further impact on the patients existing psychological trauma.

Saadia explained the long-term psychological effect of cancer:

I’m not with it at the moment, but you come to live with it don’t you. (Saadia: lines 44-45)

It could be inferred that Saadia’s experience of the cancer treatment trauma has become a part of her.

2.4.1.2.2 Meaning making.

The analysis revealed that the participants attempted to make sense of their cancer experience during their treatment journey. Saadia illustrated this:

I thought... well why me? You know, erm, everybody else was there, why particularly me? And I couldn't get to terms with it.

(Saadia: lines 42-44)

Interpretation of this may suggest that for Saadia having cancer may be unjustified.

Additionally, the participants re-examined their religious beliefs as part of the meaning making process:

You wouldn't believe that after this had happened to me, everything I [had] done [was] gone, my [religious faith] [felt] completely blank. I told Dr X [Clinical psychologist] this, as I had so much faith in Sai Baba [Hindu Saint] and Ambaji [Hindu Goddess]... I believed [in them] so much. But when I heard the cancer [word]... I ask[ed] God 'Why me? What did I do wrong?' [My religious faith] all went out of my mind. (Indumati: lines 316-322)

Indumati reported a spiritual disconnection with her religion when she was diagnosed with cancer. Before cancer, she had a strong religious Hindu faith and this was questioned after the diagnosis. However, Indumati stated that she had not lost

faith in religion in general, as she explained that she began to feel more connected to Christianity and began to attend the church during her recovery phase:

When we went there she [Indumati's friend] told the vicar, "she [Indumati] has this problem", they have sick people who go there, so everybody prays for them. You wouldn't believe it but I really liked it. Then after that, I went continuous every Sunday to the church. (Indumati: lines 362-366)

Saadia described a strengthening of her religious faith:

I [felt]... no... I want[ed] to be in comfort with God because at the end of the day... He gave me this disease or whatever you call it and I believe[d] He [was] testing me to see how much I [could] take of it...how I confided in Him and how I ask[ed] for His help. (Saadia: lines 128-132)

Saadia's experience contrasted with Indumati's disconnection with her existing faith and reconnection with a new faith. It may be that Saadia had made sense of her cancer experience by seeking answers from her existing faith. These findings highlight that some South Asian women use their religious beliefs to help them cope with their difficulties.

2.4.1.2.3 Psychological therapy.

The experiences associated with having therapy included positive feelings of relief, and letting problems out. Indumati described her experience of managing her emotions:

What it felt like was the pain that I had kept inside me I took it all out...because I had filled it all inside [me] and sat with it.
(Indumati: lines 291-292)

Saadia used the metaphor of ‘spilling out’ the emotions that had been kept inside of her. She described that having someone listen to her was of great value:

[the psychologist] let me just speak and spill out, I think somewhere along the [line] I did break down and she did listen to me quite a bit...she listened and I suppose I needed someone to listen to me. (Saadia: lines 115-118)

The experience of psychological therapy has been described positively. It could be interpreted that participants felt able to disclose their hidden feelings to the psychologist who was there and willing to listen.

2.4.1.2.4 Strengths and hope.

The participants also highlighted how psychological treatment had changed their focus and provided a sense of hope:

Every 27th January I think [about it] every time. Two years have passed and I haven’t realised. (Indumati: lines 309-311)

Indumati described that the passage of time was a significant indicator in her recovery from cancer. It could be that Indumati remembered the date of her operation to remove the cancer, which was a significant anniversary for her. It appeared that she viewed the years passing as positive and felt a sense of personal growth from her experience.

Sharanjeet took an active stance to her revival by choosing to live her life, this highlighted another example of recovery:

I've got to live my life, I can't keep worrying about it 'cos then
I'm not going to really enjoy my life... so I try and you know, I
have good days and bad days. (Sharanjeet: lines 184-187)

The psychological experiences of the cancer journey described suggest that cancer had made a long-lasting impact on the participants. Despite the challenging experiences depicted, the participants alluded to psychological strength and growth from the experience.

2.4.1.3 Family, friends and generations.

During the interviews participants shared the importance of family and friends, of how they reacted to the illness and how their support was variable. They also identified the differences in the responses between the younger and older generations.

2.4.1.3.1 Emotional effects on the family.

The participants reported a range of emotions expressed by their family members. Some family members mirrored the participant's reactions, such as fear and shock. Indumati responded to cancer with tearfulness and despair and her husband expressed similar feelings:

My husband spoke to the Nurse and [he] began to cry...

(Indumati: lines 179-180)

In contrast, Navpreet said that her father could only express his fear and pain by becoming angry. Navpreet was able to understand why her dad responded to her this way:

I think my dad was scared at the time, that's why he was screaming and shouting and that was his way of... he didn't know what to say to me. (Navpreet: lines 560-562)

The emotional responses expressed by the participants' families ranged from despair to anger. The description of those experiences may suggest that participants could accept their families' emotional responses of distress.

2.4.1.3.2 Practical support.

Some participants explained that their family were by their side at the important times. Indumati described that her family were with her on the day that she received the diagnosis:

We all went, me, my daughter and my sister and my husband we all went up there. They called us for the results. And we all sat there and the doctor was sat there in the room. (Indumati: lines 37-40).

Navpreet also described her experience of her close friend helping her to regain independence:

...my friend X came, you know from the states, she [the psychologist] knew I had people around me that would support me like my friend who came and visited me and spent couple of ...what it was like ten days with me and got me back in the gym. (Navpreet: lines 245-248).

2.4.1.3.3 Lack of emotional support.

However, despite the benefits of having the family around, the participants also felt that family could not provide emotional support, as they were unable to empathise with their situation:

I couldn't speak to anyone. I [turned] to my husband, my husband cried, and I [turned] to my daughter, my daughter cried,

[and] my sister too. Who could I turn to? I couldn't [talk about it] with nobody. (Indumati: lines 292-296)

Indumati highlighted that there was a contrast in her experience of her family 'being there' and being emotionally absent at her time of need.

2.4.1.3.4 Generational differences.

Another emergent theme that developed from the data was the difference between the younger and older South Asian generations. Most of the participants were clear that younger generations were better able to cope and openly express what they were experiencing, whereas older generations coped with cancer differently as they were less likely to access services or communicate their difficulties. Saadia provided an example of this:

But the elderly, it's just like one of those things you just get on with it, [you] don't need a psychologist...they're for the English people and not [us] and why [should we] go to them. (Saadia; lines 252-254)

This finding may suggest that older South Asians may not accept psychological treatment as they viewed adversity as part of life and services were not suitable for South Asian communities.

2.4.2 Themes from the Focus Groups

2.4.2.1 The challenges faced by them and us.

The superordinate theme which emerged from the focus group data was the challenges faced by staff and South Asian patients (see table 4). All key informants described experiences of working with South Asian cancer patients and their families. The exploration of group dynamics highlighted that themes were co-created using personal key informant experiences. This interaction affected the way the themes were expressed between key informants within the groups as they were intertwined with one another. Additionally, the complex issues raised created some tensions within discussions with the ideas expressed between the group members.

Table 4. Focus group superordinate theme and emergent themes

Superordinate theme	Emergent themes
The challenges faced by them and us	<ul style="list-style-type: none"> • They have family support but not emotional support • Family translators may create shame and embarrassment with the patient • Asian families do not translate accurately • Asian families want to protect patients • Asians don't listen because of their beliefs • Staff have to provide a standard approach

2.4.2.1.1 *They have family support but not emotional support.*

The key informants were aware that family support was a key component in South Asian culture. They highlighted that some patients, in particular women, often attended services with the support of their families:

We did have a scenario in one of the consultant clinics yesterday afternoon an Asian lady came with five of her family members from the grandson to the daughter in law... (K6: lines 72-75)

This finding contrasted with another view that families may not emotionally support South Asian women. This was recognised by the K2, who addressed that South Asian women had a lot of pressure. Within this extract, K2 stated her position as an Asian woman by her use of language and identified the existence of the limited support from the community:

I think if women who get cancer in our community, they are still expected to carry on and the matriarchal role is [still] expected to carry on in making chapattis for dinner or chips or whatever. (K2: lines 175-178)

2.4.2.1.2 Family translators lead to shame and embarrassment.

Key informants were aware of the difficulties that non-English speaking Asians experienced. In this extract, a key informant talked about an experience of attempting to provide emotional support, however this proved difficult due to the family having to translate for the patient:

...you are talking to [the] relative and not the patient...and eye contact is limited. To deal with talking, looking and the language, it's all directed at the relative...with communication skills and everything, it's all one to one...and then when you are trying to

talk to a grandchild or grandson about her feelings... (K6: lines 95-100)

Additionally, this discussion gave emphasis to the potential difficulties the patient may have experienced, such as embarrassment and shame:

That's going to be difficult for them, [when you are] asking especially with [issues to do with] bowels, it's even more, sort of embarrassing, when if you have a younger member asking an older [person]. (K4: lines 101-104)

K6 highlighted the task of attempting to provide emotional support for the patient who was distressed. She expressed her frustration of not providing the support to the patient directly. This issue was further explored by K4, who emphasised the sensitivity of talking about intimate issues between different generations. By highlighting this, the discussion raised the complex dynamics that occurred between the patient, staff and family members.

2.4.2.1.3 Asian families do not translate accurately.

Key informants raised problems experienced by staff when family members provided translation for patients. They spoke about how language barriers created difficulties for staff when providing their service. In the extract below, K4 addressed that older South Asian women in particular have language difficulties:

It's a language difficulty with the older groups especially with the women... isn't there? We don't always feel they [understand] and

whether the family are interpreting exactly what you want them to say. (K4: lines 11-15)

Further to this K4 highlighted that families may be acting as a barrier between the patient and staff. K5 extended the dialogue by stating the consequences of the family creating barriers:

And there have been occasions where they have not actually translated what we have asked them to tell the patient... and [as a result] we have had to get external translators to actually explain [the treatment to the patient] because we can't treat the patient if not. (K5: lines 15-20)

This excerpt illustrated the sense of frustration from the key informants, as these barriers impeded on the treatment service they provided and at times created complications with informed consent.

2.4.2.1.4 Asian families want to protect patients.

Another issue highlighted by key informants was that families did not want to inform the patient of their cancer diagnosis and was raised in both focus groups.

K2 raised this issue:

A lot of families know the full story when the patient is actually diagnosed. But they then say to the [staff] "as of now don't tell the patient" or they say "[the] patient only knows this amount of information". So you are then in this awkward bubble really and I think that you end up supporting different people, with different emotional needs. (K2: lines 423-426)

K2 positioned herself as a staff member and she addressed the conflict created by this family barrier. However, K3 provided the perspective from the Asian families:

But you see [the] thing is, [do] you know why we say don't tell patient? Sometimes the patient, like I just said, it didn't hit him, but we still told him...and [then] all of a sudden it hit him and he might [have] [gone] somewhere else. He's [should have been] going home or [he] might [end up] be going somewhere else...he doesn't know what he is [was] doing, things like that... and all this [these issues] comes into your mind. What shall [can] we do? How can we tackle this and what can we do? I mean couldn't go home... (K3: lines 427-434)

K3 positioned herself as a South Asian person who supported the reasons to protect the patient from their diagnosis, as she believed the elderly could not handle the diagnosis. Her use of the word 'we' highlighted this position. This distinctive stance was possibly due to her specific experience of having to translate a cancer diagnosis to an elderly South Asian patient. Thus, her challenging experience may have influenced her position.

2.4.2.1.5 Asians do not listen because of their beliefs.

One focus group discussed the impact of the limited acceptance and support from professionals:

...But once you are out of the door, they talk about different things... [as if] [the problem] doesn't exist, the things we talked about before [were ignored]...but especially the girls nowadays are suffering a lot in [the] Asian community, with this mental health. (KI3: lines 215-219)

K3 raised the issue of emotional distress within cancer and K2 agreed with this:

I think I was just going to say that a lot of this does lead to mental health, depression. (K2: lines 220-221)

K3 expanded the discussion by emphasising the cultural beliefs and stigma associated to mental health problems:

They don't realise that she needs medical help. They think, no...something [has been] done to [the woman] or [believe it is] this 'black magic', they believe in [that] a lot. [Mental health problems] ruin the families' [reputation]... [and] the husband doesn't support her. In that kind of situation sometimes we think what can we do? (KI3: lines 22-226)

This collaborative viewpoint emphasised potential reasons for emotional distress and mental health problems to remain hidden in the South Asian community. K3 illustrated her specialist knowledge of the communities and scrutinised the attitudes of South Asians. Her position in this instance was a South Asian professional looking inwards to the Asian community. Her language use of ‘they’ and reference to the Asian community as an external group supported this position.

2.4.2.1.6 Staff provided a standard approach.

Key informants reported use of adopting a standardised approach, Key informants stated they “...try and just treat everybody just the same.” (K6: line 343). However, they were also aware that this approach may not be suitable for South Asians as another key informant described, that they “... probably end up offending them”. (K4: line 344).

In the excerpt above, K6 stated how they provided standardised support to South Asian patients. This finding suggested that key informants adopted this approach because of challenges of working with South Asian families and the limited availability of the service resources to overcome the barriers. The response from K4 may have resulted from her critical reflection on the suitability of this approach in light of the discussions that had taken place within the focus group.

The overall analysis conducted revealed a number of themes that illustrated the beliefs, experiences and challenges of South Asian women and key informants. These are discussed further with reference to the implications of the findings.

2.5 Discussion

The current research explored the experiences of South Asian women who accessed psychological treatment within a cancer service using semi-structured individual interviews. The experiences of key informants who had provided services for South Asians were also sought using focus groups. Analysis using IPA found a number of themes that highlighted the experiences of psychological treatment and of the whole cancer treatment journey. The findings illustrated the psychological experiences, challenges and complicated issues South Asian patients faced. The data also highlighted the issues that concerned the key informants. The data from the South Asian participants was discussed in relation to the key informant's findings.

Analysis of the interview data revealed that South Asian participants held varied perceptions about psychological and mental health services. These beliefs depended upon family and personal experiences. Negative perceptions of mental health services were reported as some South Asian participants believed that mental health services had been unhelpful to their family members who had mental health illnesses. The participants reported that accessing such services led to stigma. However, participants who had accessed services reported positive experiences and did not associate stigma to accessing services. These findings may suggest that negative beliefs about mental health and psychological services held by South Asian women might influence access to services. In contrast, the participants who had accessed services held positive beliefs about services and were aware of the stigma associated with services. However, these participants felt that these beliefs did not apply to them as the women reported positive benefits from accessing the services. This research supported existing literature which identified the influence of stigma of accessing psychological services within South Asian Women (Anand & Cochrane,

2010; Byrne, 2000; Gary, 2005). These findings also highlighted that these barriers to accessing psychological support also existed within cancer services.

The participants spoke about the complex and varied emotions associated with their cancer journey. The emotions reported at diagnosis ranged from intense fear, despair, anxiety and reluctance to acknowledge the diagnosis and were also reported by Roy et al. (2005). It could be interpreted that these emotional reactions were a result of the participants' appraisal of their cancer diagnosis, as they South Asians believed that a cancer diagnosis was fatal, as supported by findings from Gurm et al. (2008) and Roy et al. (2005). Therefore, South Asian participants may have felt that their life was under threat and this experience could be interpreted as traumatic for the participants. Research investigating white patient's cancer treatment experience has suggested that a cancer diagnosis may result in a trauma response in patients (Bard & Sutherland, 1955; Gurevich, Devins & Rodin, 2002; Kangas, Henry & Bryant, 2002). de Groot (2008) clearly supported this by stating that "the chronic nature of the threat to life and to bodily integrity posed by cancer followed from the initial diagnosis to diagnostic and treatment interventions, and on through recurrences and the fear of recurrence" (p.28). Additionally, the participants stated that they felt overwhelmed by the process of the cancer treatment. The participants also experienced feelings of grief and loss as consequences of treatment, which was found to be a common response and is reported in the literature (Maunsell, Brisson & Deschene, 1992). The supplementary feelings may have further contributed to the psychological distress experienced by participants. Additionally participants reported being exposed to further intrusive treatments and were left with physical and psychological scars.

Limited awareness of the cancer treatment process was also reported and Randhwa and Owens (2004) found this amongst sample South Asian cancer patients in Luton, UK. The limited awareness of cancer treatments and fatalistic responses to cancer diagnosis may have rendered the South Asian participants at risk to further psychological distress.

Another psychological consequence was the attempt to make sense of their illness. This process has been widely researched within the literature (Coward & Kahn, 2005; Lee, Cohen, Edgar, Laizner & Gagnon, 2004). The participants may have felt that a cancer diagnosis was unjustified and occurred in those who engaged in cancer risk increasing behaviours such as cigarette smoking and alcohol consumption. However, these women could not piece together the reasons for their ill fate. As part of this process, religious beliefs were either strengthened in line with Gurm et al's (2008) findings or weakened as found in this study. One participant felt that her religious faith in Islam had strengthened and that she did not need psychological therapy for this reason. Research by Cinnirella and Lowenthal, (1999) and Harandy et al. (2010) had found that Pakistani-Muslim women were more likely to use religion as a coping strategy for their psychological distress, which supported the findings of this study. The impact on religion suggested that South Asian women may rely on their religious faiths to help them make sense of their illness and use it as a coping mechanism for their distress. This could also explain the loss of faith of own religion in another participant and her development of a new faith in Christianity to aid recovery.

It was noted that at first the participants were sceptical in accessing psychological treatment possibly due to stigma. However, all of the South Asian

participants described the benefits of the psychological treatment they had received. Additionally the participants who continued to seek support gained a sense of hope and strength. They mainly spoke about the benefits of the relationship they had developed with their psychologist. This was suggested to be more important than the content of the sessions and is supported by findings from Maccormack et al. (2001). This highlighted that providing a supportive relationship during a distressing experience may be beneficial for the South Asian women during their cancer treatment. The importance of providing this to South Asian women may be of pertinence as these women may not have other emotional support systems which they could access readily.

The participants spoke about the influence of their families and friends as an important component of their cancer journey. The emotional impact of the cancer diagnosis on their families was reported. The participants also stated varied experiences of support provided by their families. It was observed that practical family support and advocacy was perceived positively amongst participants and this is also reported in the literature (Balneaves et al., 2007). The intense involvement found in South Asian families may have placed the family members at risk for psychological distress, as they were often reported to be present with the patient at the point of diagnosis. The participants reported that their family members were distressed by the impact of cancer and Northhouse et al. (2002) found this in non-Asian families. The psychological impact on families may have also affected their ability to provide emotional support to the participants. Participants felt that family members were consumed with their own emotions or did not appear to be empathic to the participant. It could be interpreted that emotional responses to cancer from Asian family members may be more catastrophic due to the cultural beliefs of

cancer. Edwards and Clarke (2004) found that the distress levels within families increased and as result, families often failed to communicate their issues. The limited communication about their distress between family members may reinforce the perception of stigma related to the beliefs about emotional pain. This ‘censoring’ of emotional expression by Asian families may further contribute to the deterioration of patient’s emotional well-being and discourage distressed cancer patients to seek external psychological support.

The participants also identified differences between the younger and older generations within the Asian community. Young Asians were perceived to be more aware of the emotional issues associated with an illness and the older Asian generation rejected the use of psychological treatment. This difference may be due to stigma and the rigid cultural beliefs about psychological distress held by older South Asians. The difference in generational attitudes may imply that younger South Asians felt less influenced by cultural beliefs and stigma. This could be an influence of acculturation as young Asians may have good English language proficiency, increased education and awareness of cancer support services.

The main theme which emerged from key informant interviews was that challenges existed for South Asians to access services and that the staff had difficulties working with this group. Key informants acknowledged that families were an integral support mechanism to cancer patients. They reported that families advocated and translated for the patients however, this often resulted in complications. Key informants reported that South Asian families supported patients as they reported that South Asian women would attend clinics with many family members. Despite the strong presence of family support, key informants were aware

that South Asian families may not be emotionally supportive to the patients' distress. The key informants were able to identify challenges faced by South Asian women who may have cultural pressures, which may affect their emotional wellbeing. The limited emotional support within Asian families was also highlighted in the South Asian interviews and suggested that this is a key concern for the patients and staff.

Key informants also implied that the family advocating and translating for the patients resulted in the discussion of highly sensitive information in the presence of the family members. Key informants were aware that this resulted in shame and embarrassment for the patient. This issue could also be construed as an additional barrier to accessing of services for South Asians who do not speak English, as they may attempt to avoid the feelings of shame.

Key informants reported that they were further confounded by language barriers, as they believed Asian families limited disclosure and filtered information affecting confidentiality and informed consent. Balneaves et al. (2007) reported that South Asian families would often withhold information from patients. Within the interviews, it was noted that some key informants who were South Asian were able to understand the reasons for limited disclosure as they held the beliefs that South Asians were unable to cope with a cancer diagnosis, as illustrated by the earlier findings that South Asian participants' beliefs about cancer were fatalistic. The key informants stated that protection for South Asian patient's emotional well-being led to ethical complications for staff, as it was in the patients' best interests to be aware of the diagnosis and treatment procedure.

Another issue raised by key informants was that South Asians lacked acceptance of service support because of their cultural beliefs. They were also aware

that the resistance may impact on the wellbeing of the South Asian women. It could be interpreted that a reluctance to seek external help may be linked to feelings of shame and impact on family reputation, as reported by Gilbert, Gilbert and Sanghera (2004). Furnham and Malik, (1994) found that impact on shame and family reputation resulted in keeping emotional problems within the family and may have contributed to further isolating the patient in distress from accessing external support. This finding was also emphasised by the South Asian participants as they felt that their families lacked empathy to their emotional needs.

Due to the challenges of communication and family barriers, the key informants often felt they resorted to providing a standardised approach. Key informants were aware that this type of approach may not be suitable for meeting the needs of the South Asian patients, as they may not be culturally sensitive. However, it could be construed that key informants felt that this approach was the only way to resolve the cultural barriers they faced with South Asian patients and their families.

The findings from the in-depth individual interviews and focus group results suggested that key informants supported the beliefs and experiences reported by South Asian women. It was found within the focus groups that some key informants who were Asian, identified with their Asian culture. They either positioned themselves as an Asian woman or an Asian staff member. This finding of switching between positions is highlighted in the literature that discusses the 'representation of the other' (Wilkinson & Kitzinger, 1996). In this study, the South Asian key informants either assert their position aligned with the staff perspectives or alter their position as a South Asian woman who felt the cultural demands.

2.5.1 Limitations

There are several limitations of the current study. Firstly, the study recruited a small sample of South Asian participants and a small number of key informants. The study expected to achieve a larger sample however; a limited number of South Asians who accessed the service prevented this and the sample could be increased by including South Asian carers of cancer patients and South Asian patients with terminal cancer diagnoses. However, inclusions of these samples were not appropriate as these individuals may have differing experiences and concerns and thus dilute the analysis. Additionally the samples were all women and findings cannot be generalised to South Asian men. The 'women only' sample was the result of a lack of men volunteering to participate in the study and a limited number of men who had accessed the psychological service. Due to the different backgrounds of the participants, results reflect the divergence within particular themes and results may not be generalisable to all South Asian women groups who may speak different languages or practice alternative religions. However, the convergence of themes are also present in the results and highlight the common experiences raised by the South Asian women and key informants.

Further limitations of the study were that the key informants who participated were all women and the key informants included may have not represented all staff perspectives working within cancer service. All staff working in cancer services were invited to participate in the study and were provided two opportunities to partake in the focus groups. A possible solution to increase sample size is the inclusion of a number of cancer services. On the other hand, this would not be appropriate as regions may have specific localised issues, which would not be

emphasised within the analysis. Despite the methodological limitations this study presented, the findings highlighted some important issues.

2.5.2 Implications for practice and recommendations for future research

The current research study highlighted a number of explicit issues of concern for clinical services. Firstly, the issue of the impact of cancer on the South Asian patients and their families highlighted that South Asians may hold particular beliefs about cancer and related illnesses that may result in catastrophic emotional reactions. Clinical staff working with South Asian patients need early recognition of distress symptoms as this may help to reduce the development of further psychological distress. The common perception that South Asian patients are supported by their families requires exploration from staff as patients may need additional psychosocial support throughout their cancer treatment. Staff should also be aware that Asian families may not always pass on accurate information for their beliefs of patient protection and this may result in the patient needs not being met. It is suggested that thoroughly trained translators are utilised to overcome language barriers where available, as this will eradicate any censorship and embarrassment issues for the patient. Despite the benefits of external translators, this solution does not remove the issue of generating a therapeutic relationship between the clinician and the patient. Another option could be to introduce more multi-lingual South Asian staff. However, it should not be assumed that all South Asian patients feel comfortable with South Asian staff, as issues of confidentiality may affect the relationship. Thus, patients should have the right to choose their practitioner to enable better therapeutic relationships with patients. Unfortunately, due to health service restraints these service provisions are often not possible. Therefore, all clinical staff need additional training in cultural awareness and to be better informed on how to deal with South

Asian patients in a cancer context. Staff also need to recognise the impact of psychological distress in Asian families and encourage better communication between family members. This will encourage better emotional support within families and help reduce beliefs of stigma associated with mental health issues and accessing services. Better education is needed within South Asian communities about the psychological consequences of cancer and cancer treatment. This will inform and empower communities to recognise symptoms earlier and to encourage better engagement of South Asians to clinical services.

Future research may consider extending this study by including the perspectives of family members and from South Asian patients who do not access psychological support. This investigation could provide insight into the support mechanisms that South Asians with cancer utilise, and may help services to create links with these resources. Additionally, the impact of cancer on South Asian men had received limited attention and could be further investigated using qualitative research methodology. The perspectives of terminally ill South Asian patients and carers may also be considered for future research. Further research could also investigate experiences of specific South Asian groups living in the UK.

2.5.3 Conclusion

This exploratory research aimed to investigate the experiences of psychological treatment within a sample of South Asian women with cancer and include key informant experiences. The study highlighted a number of factors which included the emotions and challenges that the participants faced during their cancer journey. The participants described the utility of psychological treatment and discussed the impact of cancer on their wider systems. Key informants provided

perspectives of challenges faced by the South Asian patients and the staff who provide support services to them.

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Chapter Three:

South Asian Super Heroines

Word count (excluding references): 1,998

Article prepared for submission to Journal Psychology of Women Section Review
(Agora section) (See appendix 3 for notes to contributors)

3.1 Introduction

This article discusses my reflections on carrying out the research that formed part of my doctoral thesis in clinical psychology. The empirical research was an explorative study, which investigated the experiences of psychological treatment in a sample of South Asian women with cancer. Reflections on the research process were taken from a research diary that I used throughout the study. The reflections elicited a number of themes to include the factors that inspired my interest in the research, the issues of sameness and difference, empowerment of storytelling, and finally the impact of the research on the researcher.

3.2 South Asians and psychological research

Being British South Asian myself, I have a strong interest in cross-cultural psychology. My interest in ethnicity developed from my awareness that limited numbers of South Asians access psychological services. I have a longstanding interest in exploring the reasons for this and to also understand how services can be improved to more adequately address the needs of these communities. This interest influenced me to conduct research that investigated the psychological issues that the South Asian community experience when diagnosed with cancer.

My grandfather was diagnosed with cancer in 2004. Up until then I had only heard about ‘other people’ being diagnosed with cancer. Cancer was a word which people in my community feared and it was a phenomenon that was whispered about. On one August evening in 2005, myself and my family were by my grandfather’s side to witness his soul set free from his body. On reflection, I did not recall any support services in place for my grandfather prior to his death, or for the family. This made me wonder, what my grandfather would have wanted from the services if he was aware of them. What were his fears? What difference would the involvement of

services had made to him? This experience inspired me to think about how South Asians cope with cancer and what encourages them to seek psychological support.

I chose a qualitative methodology for my research for three reasons, the first being that a quantitative research methodology was not appropriate for the sensitive nature of the topic. Secondly, I wanted to gain an in-depth understanding of the South Asian cancer patient experience and hoped that this would provide them the opportunity to speak freely. Finally, I wanted to use this methodology because I have had limited experience in conducting qualitative research and this provided me an opportunity to acquire new skills in this research methodology.

3.3 Issues of ‘sameness’ and difference

The study recruited a sample of South Asian women that had a diagnosis of cancer and had accessed the psychology service. When I began interviewing, I had no idea of what it would feel like to be asking intimate questions about emotional experiences for research purposes. On reflection of the interviews conducted, I realised that the women allowed me into their lives and to listen to their intimate accounts of their cancer journey. They spoke about the emotional damage that the cancer had caused and they explained that their family systems were also affected. I wondered whether this intimate detail about Asian culture would have been addressed if I was not South Asian myself. Bhopal (2001) discussed this issue and highlighted that ethnicity and gender play an important role in the research with ethnic minority populations. I feel that being a South Asian woman gave me an advantage, as often the women included me in their world by stating: *“you know how it is in our community”*. Quite often, I did know and I would often react naturally by nodding my head and smiling encouragingly. The mutual understanding of what it feels like to be a South Asian woman living in the United

Kingdom created a relationship between us. However, there were distinctions between the participants interviewed as the impact of my identity also may have limited the detail of the interviewees account (Song & Parker, 1995). An example of this was when Saadia, a participant in the study, highlighted that I would think it was 'weird' that she had a deep spiritual connection with God. Her assumption that I did not have strong religious beliefs was correct and could have been derived from her assumption that I was not Muslim. Song and Parker (1995) suggested that these assumptions that participants often make about researchers may impact on the level of detail and disclosure within interviews.

This experience has highlighted that within qualitative research the interviewers' qualities are also an influencing factor and should be considered in the research process. Being aware of this has made me realise that there was variability in the disclosure of content between the participants/women I interviewed. However, I feel that the women were able to speak to voice their experiences of their cancer treatment.

3.4 Empowerment and story telling

The women's experiences were full of detail and rich description. I underestimated the impact of their stories would have on me. I remembered feeling in awe of these women that fought cancer and battled with their cultural barriers to access the help and support they needed. These women were 'super heroines' in my eyes. These stories have enlightened my perspective of South Asian women who have suffered with cancer and thus I wondered if the women also were impacted by the research. The nature of qualitative research has been found to elicit empowerment within the participants and has been supported by early research (Klienman, 1988; Mishler, 1984). Feminist psychology and community psychology

researchers have argued that qualitative research encourages the use of narrative stories which empower women and ethnic minorities (Banyard & Miller, 1998; Mies, 1983). I felt that the women that I had interviewed may have experienced a sense of empowerment as I had explicitly stated that I wanted to hear their experiences to help inform research and treatment services from the point of recruitment. The women interviewed were very humble when I explained the importance of their experiences and they acknowledged that they too shared my concern for development of research and services to support the South Asian community.

My intentions were to explore the South Asians women's experiences of psychological therapy. I wanted to engage the participants in the research and therefore, I chose to be flexible with the use of my questions within the interviews. The women chose to begin their accounts wherever they felt comfortable. All of the women who had no prior experience of psychological therapy began their stories from the point of screening for cancer. It felt that these women wanted me to hear their experiences of their cancer journey from the very beginning. Often the stories contained negative experiences of the medical system being chaotic and unsupportive. The most emotional point of the interviews were when the women spoke about the moment they were diagnosed and were often tearful when they spoke. The pain was real and I could feel it in the room. I began interviewing these women when I first began my placement with the cancer service team. Therefore, I felt I was naive to the emotional experience of the psychological effect of cancer. The experience of interviewing these women and being in the researcher's position made a difference to how I experienced their emotions. I was more able to listen to their accounts intently as I was free from intervening psychologically. However,

sitting with their distress during the interviews was difficult as I had a strong desire support and ask further questions, which would have resulted in contamination of the interview data.

The experience of storytelling may have given the women a chance to continue to make sense of their cancer journey. As there were parts within the interviews the women would stop to reflect on their thoughts and experiences. I wonder if they have had the opportunity to do this with anyone else. Having conducted this type of research I can look back and think about the impact that it had on myself but am unable to explore the potential impact on the people involved.

3.5 Impact on the researcher

Upon reflection, I felt that I identified with the participants as more than I would have with non Asian women. The women reminded me of those I knew, like my mother, my aunties and other Asian relatives. Being Asian myself, I could understand the strains that the women encountered and the cultural demands placed on them. I related the experiences that I had in my life of how people I knew coped with adversity with the additional challenges of being Asian and living in the UK. Some of these were unspoken but I could easily identify and imagine what these may have been like.

By attempting to put myself in the shoes of these women I became more aware of the emotions related to cancer. The women all highlighted that cancer meant death to them. Their emotional reactions to their diagnosis corresponded to these thoughts. Hearing the stories of the women about their diagnosis did produce strong emotions from the women. Sitting with their fears of death was difficult. Seeing their tears was also challenging. Women were telling me about how they really believed that they were going to die. This was something that they may not

have told many people. Interviewing the women and listening back to the audio recordings was something that I realised that I avoided at first. I did feel upset and emotional when they became emotional. When I did eventually pluck up the courage to listen, the narrative within the interviews highlighted the challenges that the women faced with mortality and being an Asian woman. The women have taught me that in the face of adversity, Asian women struggle because of their beliefs however this does not stop them from fighting. The women were able to tap into their own personal strengths be it religion, their family, friends or partners for support and motivation to live. This has inspired me to think about the women that may not have accessed services. In addition, wonder what resources they have accessed instead.

Future research needs to hear from the women that do not access services and services are urged to learn from them. As there is the negative stereotype that Asian women are passive recipients to services or that they don't access service because of their lack of education and understanding. What this research has taught me is to have an open mind as I know that I held perceptions about the women due to my own position and experiences as an Asian woman who lost a relative to cancer. Moreover, some of these were in line with the general stereotype. The women I interviewed had diverse experiences and this has made me realise the array of types of south Asian women living in the UK. I have taken away with me that qualitative research is also challenging. Learning to make sense of vast amounts of data has been not only time consuming but also exhausting for me. I thought that being a South Asian woman would make it easier; however I am not a South Asian woman who has had cancer treatment. Therefore, this was a challenging and emotional experience.

3.6 Concluding remarks

This article included reflections on the research I carried out as a British south Asian woman. I have found benefits in researching a sample of women that were of similar ethnicity to me. Despite the beliefs that ethnic matching would result in more open and truthful accounts my own research indicated that this is not always the case. I have learnt from the process of qualitative research that the process is complex and challenging. The results of the research are rich and this outweighs the challenges of the research process. I feel that more research is needed especially with women from minority ethnic groups as this will encourage more marginalised ethnic groups to participate in research and enable their voices to be heard.

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APPENDICES

Appendix 1: Instructions for Authors Journal of Ethnicity in Substance Abuse

Instructions for Authors

The *Journal of Ethnicity in Substance Abuse (formerly Drugs & Society)* presents rigorous new studies and research on ethnicity and cultural variation in alcohol, tobacco, and other drug use and abuse. The research is drawn from many disciplines and interdisciplinary areas in the social and behavioral sciences and helping professions. The journal is an important addition to current addiction studies education, providing background knowledge and intervention techniques to educators, policymakers, and practitioners working with today's diverse client population. The Journal of Ethnicity in Substance Abuse is an international forum for culturally competent strategies in individual, group, and family treatment of alcohol, tobacco, and other drug abuse. The journal also offers strategies for program development and evaluation, prevention programming, and harm reduction strategies that are ethnically or culturally appealing. This journal systematically investigates the beliefs, attitudes, and values of substance abusers, searching for the answers to the origins of drug use and abuse for different populations. The journal has several regular features, such as "In Brief," which consists of news articles significant to ethnicity. The journal also publishes letters, reviews of print and nonprint media, and listings of significant Web sites for further investigations.

Address manuscripts to the Editor:

1. Authors are strongly encouraged to submit manuscripts electronically. If submitting a disk, it should be prepared using MS Word or WordPerfect and should be clearly labeled with the authors' names, file name, and software program.
2. Manuscripts should be submitted in triplicate/duplicate to the Editor, Peter L. Myers, PhD - JourEthSubAbuse@gmail.com - 82 Willow Street, Brooklyn, NY 11201

Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become the property of the publisher.

All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of not more than 100 words. Avoid abbreviations, diagrams, and reference to the text in the abstract.

References

APA references, citations, and general style of manuscripts should be prepared in accordance with the APA Publication Manual, 4th ed. Cite in the text by author and date (Smith, 1983) and include an alphabetical list at the end of the article.

Examples: Journal: Tsai, M., & Wagner, N. N. (1978). Therapy groups for women sexually molested as children. *Archives of Sexual Behaviour*, 7(6), 417-427. Book: Millman, M. (1980). *Such a pretty face*. New York: W. W. Norton. Contribution to a Book: Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.), *Ageing in the 1980s* (pp. 239-252). Washington, DC: American Psychological Association.

Illustrations

Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.) should be clean originals or digital files. Digital files are recommended for highest quality reproduction and should follow these guidelines:

- 300 dpi or higher
- Sized to fit on journal page
- EPS, TIFF, or PSD format only
- Submitted as separate files, not embedded in text files

Color Reproduction

Color illustrations will be considered for publication; however, the author will be required to bear the full cost involved in color art reproduction. Color art can be purchased for online only reproduction or for print + online reproduction. Color reprints can only be ordered if print + online reproduction costs are paid. Rates for color art reproduction are: Online Only Reproduction: \$225 for the first page of color; \$100 per page for the next three pages of color. A maximum charge of \$525 applies. Print + Online Reproduction: \$900 for the first page of color; \$450 per page for the next three pages of color. A custom quote will be provided for articles with more than four pages of color. Art not supplied at a minimum of 300 dpi will not be considered for print.

Tables and Figures

Tables and figures (illustrations) should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet.

Proofs

Page proofs are sent to the designated author using Taylor & Francis' Central Article Tracking System (CATS). They must be carefully checked and returned within 48 hours of receipt.

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Appendix 2: Notes to contributor for Journal of Psychosocial Oncology

Instructions for Authors

Aims and Scope: Here is your single source of integrated information on providing the best psychosocial care possible from the knowledge available from many disciplines.

The ***Journal of Psychosocial Oncology*** is an essential source for up-to-date clinical and research material geared toward health professionals who provide psychosocial services to cancer patients, their families and their caregivers. The journal—the first interdisciplinary resource of its kind—is in its third decade of examining exploratory and hypothesis testing and presenting program evaluation research on critical areas, including: the stigma of cancer; employment and personal problems facing cancer patients; patient education; family involvement in patient care; children with cancer; the psychosocial needs of cancer patients; hospital and hospice staff; and volunteers.

The journal's editorial board represents many different fields in psychosocial oncology, including education, epidemiology, health advocacy, medical oncology, neurology, nursing, nutrition, pastoral counseling, physical therapy, psychiatry, psychology, public health, social work, sociology, and surgical oncology. Regular features of the ***Journal of Psychosocial Oncology*** include: discussions of current ethical, philosophical, and existential issues; columns on research issues, strategies, and methodologies; announcements of current meetings, symposia, and courses being offered; book reviews that highlight important, new book-length works; selective bibliographies of articles that appear in other journals.

Address manuscripts to the Editor: *Journal of Psychosocial Oncology* receives all manuscript submissions electronically via their ScholarOne Manuscripts website located at: <http://mc.manuscriptcentral.com/WJPO>. ScholarOne Manuscripts allows for rapid submission of original and revised manuscripts, as well as facilitating the review process and internal communication between authors, editors and reviewers via a web-based platform. For ScholarOne Manuscripts technical support, you may contact them by e-mail or phone support via <http://scholarone.com/services/support/>. If you have any other requests please contact the journal at mailforkrish@gmail.com.

Authors must complete a Copyright Transfer Form Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become the property of the publisher.

All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be

summarized in an abstract of not more than 100 words. Avoid abbreviations, diagrams, and reference to the text in the abstract.

References. References, citations, and general style of manuscripts should be prepared in accordance with the APA Publication Manual, 4th ed. Cite in the text by author and date (Smith, 1983) and include an alphabetical list at the end of the article. *Examples:*

Journal: Tsai, M., & Wagner, N. N. (1978). Therapy groups for women sexually molested as children. *Archives of Sexual Behavior*, 7(6), 417-427.

Book: Millman, M. (1980). *Such a pretty face*. New York: W. W. Norton.

Contribution to a Book: Hartley, J. T., & Walsh, D. A. (1980). Contemporary issues in adult development of learning. In L. W. Poon (ed.), *Ageing in the 1980s* (pp. 239-252). Washington, DC: American Psychological Association.

Illustrations. Illustrations submitted (line drawing, halftones, photos, photomicrographs, etc.) should be clean originals or digital files.

Digital files are recommended for highest quality reproduction and should follow these guidelines:

- 300 dpi or higher
- Sized to fit on journal page
- EPS, TIFF, or PSD format only
- Submitted as separate files, not embedded in text files

Color Illustrations. Color illustrations will be considered for publication; however, the author will be required to bear the full cost involved in color art reproduction. Color art can be purchased for online only reproduction or for print+online reproduction. Color reprints can only be ordered if print+online reproduction costs are paid. Rates for color art reproduction are: Online Only Reproduction: \$225 for the first page of color; \$100 per page for the next three pages of color. A maximum charge of \$525 applies. Print + Online Reproduction: \$900 for the first page of color; \$450 per page for the next three pages of color. A custom quote will be provided for articles with more than 4 pages of color.

Tables and Figures. Tables and figures (illustrations) should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet.

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Appendix 3: Notes to contributor for Psychology of Women Section Review

POWS Review

The ***Psychology of Women Section Review*** provides a forum for discussion of issues and debates around all aspects of the psychology of women in research, teaching and professional practice. It aims to promote and support academic research and debate on issues related to the development of theory and practice concerning gender and other social divisions.

POWS Review encourages submissions from individuals at all stages of their career, including undergraduate and postgraduate students. It promotes a positive reviewing process.

POWS Review publishes:

- theoretical and empirical papers;
- reviews of relevant books and research;
- special issues and features; and
- short papers, commentaries, interviews and other non-traditional submissions in its 'Agora' section.

Contact:

Sally Johnson (Co-editor)

s.e.johnson2@bradford.ac.uk

Nancy Kelly (Co-editor)

n.kelly@bradford.ac.uk

Amanda Holt (Assistant Editor, Book Reviews)

Amanda.Holt@port.ac.uk

Lucy Thompson (Assistant Editor, Agora)

L.Thompson@leedsmet.ac.uk

Jemma Tosh (Assistant Editor, Research Reviews)

j_m_tosh@hotmail.co.uk

Notes for Contributors

1. All papers and submissions for the Agora section will be peer-reviewed.
2. Copies of all submissions should be sent by e-mail attachment (in Word format) and/or three hard copies to the Editors (or Assistant Editor where specified). A separate cover page should be provided with the title of the paper, the author's names, their institutions, addresses and email addresses clearly marked. Authors are also invited to provide brief biographical information. Manuscripts should have

the title clearly marked on the first page, and pages should be numbered. However, authors' names should not appear on the manuscript itself.

3. All figures should be of reproducible standard. References should conform to Society style, which is similar to the American Psychological Association (APA) system. The Society's *Style Guide* can be downloaded from:

www.bps.org.uk/publications/submission-guidelines/submission-guidelines_home.cfm

4. Papers should be between 3000 and 6000 words long, and submissions for the Agora between 200 and 2000 words. An abstract of up to 150 words should be provided with papers, however, no abstract is needed for Agora submissions.

5. Book reviews and reviews of research papers will normally be commissioned by the relevant Assistant Editors. Anyone interested in reviewing books or research papers should contact the Assistant Editor directly.

6. Authors should avoid the use of any sexist, racist, heterosexist or otherwise discriminatory language.

The views expressed in this publication are those of the authors, and not necessarily those of the organisations or institutions that they work for.

Please send all correspondence to:

Sally Johnson & Nancy Kelly

Centre for Psychology Studies

Department of Social Studies and Humanities

University of Bradford

Richmond Road

Bradford BD7 1DP

E-mail: s.e.johnson2@bradford.ac.uk

E-mail: n.kelly@bradford.ac.uk

Appendix 4: Coventry university ethical approval

Dear Tina

As you have now undergone peer review, you need to move to the next stage of the process - final sign off (section 4a of the attached flow chart).

Please find attached the insurance documentation which you will need to attach to your application. I also attach a sponsorship letter which will be signed by the PVC at the same time as your IRAS form. His PA will have a copy of the letter already printed on letter headed paper and prepared for signature.

Please note that you once you have submitted your form and supporting documentation to the NHS service you will be invited to attend the meeting at which your application will be considered. It is good practice for your project supervisor to attend with you.

With kind regards

Judy

Judy White

Assistant Registrar, Registry Research Unit

Coventry University

Jaguar Building (JA106)

Coventry

CV1 5FB

Tel: 024 7688 7029 Mobile: 07974 98 4522

Email: judy.white@coventry.ac.uk

Appendix 5: NRES Letter of approval



National Research Ethics Service
Coventry & Warwickshire Research Ethics Committee

Prospect House
Fishing Line Road
Enfield
Redditch
B97 6EW

Telephone: 01527 582534
Facsimile: 01527 582540

04 August 2010

Mrs Tina Mistry
Trainee Clinical Psychologist
Worcestershire Mental Health NHS Trust
Kidderminster Hospital
Bewdley Road
Kidderminster
DY10 1YT

Dear Mrs Mistry

Study Title: An exploration of South Asian clients' access to psychological services within oncology and palliative care in West Midlands.
REC reference number: 10/H1211/28

The Research Ethics Committee reviewed the above application at the meeting held on 28 July 2010. Thank you for attending to discuss the study.

Ethical opinion

Record of ethical issues discussed

The participants in your study are vulnerable patients who may become distressed. Are you trained for this?

You said you were a trainee clinical psychologist and have experience in dealing with vulnerable patients.

Have you permission to use Trust translators?

There is no written agreement but a contract is in place if it is required.

You are conducting interviews, some through translators. Have you any research experience?

You explained that this is the first time I have done this level of research but my supervisor is very experienced.

You are recruiting from data monitoring. How will you know if people are well enough or still alive?

Potential participants are in contact with the Community Nurses and the data monitoring is updated regularly. There is contact between all the health professionals in the community team.

Are you confident that you would know if something had happened to a potential participant?

Yes.

The indemnity runs out at the end of July.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>. Where the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Investigator CV		12 July 2010
Protocol	v3	09 July 2010

CV Academic Supervisor		12 July 2010
Demographic Details Protocol	v2	09 July 2010
REC application		09 July 2010
Letter from Sponsor		09 July 2010
Interview Schedules/Topic Guides	v2	09 July 2010
Interview Schedules/Topic Guides	v2	09 July 2010
Participant Information Sheet: Info Sheet - South Asian	v2	09 July 2010
Participant Information Sheet: Info Sheet - Key Informant	v2	09 July 2010
Participant Consent Form	v2	09 July 2010
Evidence of insurance or indemnity		01 August 2009

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk

CV Academic Supervisor		12 July 2010
Demographic Details Protocol	v2	09 July 2010
REC application		09 July 2010
Letter from Sponsor		09 July 2010
Interview Schedules/Topic Guides	v2	09 July 2010
Interview Schedules/Topic Guides	v2	09 July 2010
Participant Information Sheet: Info Sheet - South Asian	v2	09 July 2010
Participant Information Sheet: Info Sheet - Key Informant	v2	09 July 2010
Participant Consent Form	v2	09 July 2010
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- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk

Coventry & Warwickshire Research Ethics Committee

Attendance at Committee meeting on 28 July 2010

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Jane V Appleton	Nurse	Yes	
Mr Roger Balcombe	Retired Chartered Engineer	Yes	
Dr Helen Brittain - Chair	Clinical Psychologist Retired	Yes	
Mrs Barbara Canning	Senior University Lecturer	Yes	
Mr Roger Cross	Senior Clinical Pharmacist	Yes	
Mr Matthew Dunn	Consultant Accident and Emergency	Yes	
Mrs Caroline Galloway	Pharmacist	No	
Ms Evette Hutchinson	NHS Lay Member/Mature Student	Yes	
Dr Ashok Roy	Consultant Psychiatrist/Children and Adults lacking Mental Capacity	Yes	

Appendix 6: Walsall R&D approval letter

Chairman
Chief Executive

Dr Geoff Archenhold
Denise McLellan



Governance Department
Jubilee House
Bloxwich Lane
Walsall
WS2 7JL

01922 619994

23rd September 2010

Mrs Tina Oza Mistry
1655 Stratford road
Hall green
Birmingham
B28 9JB

Dear Mrs Mistry

Title of project: An exploration of South Asian clients's access to psychological services within oncology and palliative care in West Midlands

Thank you for supplying the Governance Department with the requested documentation. We are pleased to inform you that from a research point of view we are happy for you to carry out the research in accordance with the protocol you have submitted.

This permission only covers **NHS Walsall and NHS Walsall Community Health**.

The information supplied about your role in the above research project has been reviewed and you do not require an honorary research contract with this NHS organisation. The trust is satisfied that such checks as it considers necessary have been carried out. This letter outlines your responsibilities while you are conducting research within this NHS organisation.

You are considered to be a legal visitor to Trust premises. You are not entitled to any form of payment or access to other benefits provided by the Trust to employees and this letter does not give rise to any other relationship between you and the Trust, in particular that of a contract of employment.

You must act in accordance with Trust policies and procedures, which are available to you upon request, including the Research Governance Framework for Health and Social Care (2005). You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and the premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or members of staff remains secure and **strictly confidential** at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice

(<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act (1998). Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that where you are issued an identity or security card, a bleep number, email or library account, keys or protective clothing, that these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that the Trust accepts no responsibility for damage or loss of personal property.

Your substantive employer is responsible for your conduct during this research project and any breach may result in disciplinary action against you. Any breach of the Data Protection Act (1998) may result in legal action against you and / or your substantive employer.

At some point we are likely to audit your paperwork for this project and it is important that you keep everything secure, especially that relating to informed consent from participants in your research.

If there are any changes to your research, any difficult incidents or if you have queries about conducting the research, please inform the Governance Department immediately on 01922 619994

We look forward to hearing the outcomes of your research and receiving a final report. Good luck with the project.

Yours sincerely,



Dr R Gutteridge
Chair, NHS Walsall Research and Development Committee

Appendix 7: South Asian participant information letter

Date:

Dear

I am writing to you to invite you to participate in a research study which forms part of my Doctorate in Clinical Psychology. I have contacted you because you have accessed help from the Clinical Psychology Service in Oncology and Palliative care.

Title of project: An Exploration of South Asian Clients Access to Psychological Services within Oncology and Palliative care in the West Midlands.

Back ground to the study:

It is important to provide equal access to psychological services for everyone living in the United Kingdom. However, research has found that people who identified as Black or any other Minority Ethnic have poorer access compared to White people. This study aims to explore the issues of South Asian people who have accessed this psychology service. Additionally staff who work in the Oncology and Palliative care service will be invited to give their thoughts about this topic in a separate group. It is hoped that information gathered in this study will help psychology services to develop better future practice, better training and also highlight the need for further research within this area.

What do I have to do?

If you would like to take part in the study, you will need to read information in this letter. Then you will need to sign the consent form (attached) and contact the researcher so that she can contact you to arrange a suitable appointment. When you arrive for your appointment you will be given the opportunity to ask any questions about the study and if you would like to participate you will be asked to verbally consent to be interviewed, for the interview to be audio taped and the audio tape to be analysed. The interview will be audio taped, however all information will be treated confidentially and will be anonymised.

How long will the appointment last?

The individual interviews will last approximately 60 to 90 minutes depending on how much information is spoken about.

What if I agree to take part and later change my mind?

You can withdraw from the study at any point by contacting the team below. You do not have to give any reasons for this and this will not affect your rights for any treatment from the service.

Ethical approval and confidentiality

This study has been approved National Research Ethics Service for the NHS and also by

Coventry University Ethics committee. A copy of the final report will be available in September 2011 and all participants will be able to receive a summary of the results.

The researcher contact details:

Tina Oza Mistry (Trainee Clinical Psychologist)

If you wish to take part in the study or you have any questions about the study please contact the number above and leave your contact details with the secretary. The researcher will then contact you to arrange an appointment.

Yours Sincerely

Mrs Tina Oza Mistry
Trainee Clinical Psychologist
Universities of Coventry and Warwick

Appendix 8: Key Informant information letter

Date:

Dear

I am writing to you to invite you to participate in a research study which forms part of my

Doctorate in Clinical Psychology. I have contacted you because you provide a service to clients within the Oncology and Palliative Care Service.

Title of project:

An Exploration of South Asian Client's access to Psychological Services within Oncology and Palliative care in the West Midlands.

Back ground to the study:

It is important to provide equal access to psychological services for everyone living in the United Kingdom. However, research has found that people who are identified as Black or minority ethnic have poorer access compared to White people. This study aims to explore the issues of South Asian people who have accessed a Psychology service. Additionally, staff who work in the Oncology and Palliative care service will be invited to give their thoughts about this topic in a separate group. It is hoped that information gathered in this study will help psychology services to develop better future practice, better training and also highlight the need for further research within this area.

What do I have to do?

If you would like to take part in the study you will need to read this information sheet and if you agree to take part you will need to sign the attached consent form and contact the researcher so that she can contact you to arrange a suitable appointment. You will be asked to take part in a group interview with 6-8 other people conducted by the researcher. When you arrive for your appointment you will be given the opportunity to ask any questions and if you feel you would like to take part you will be asked to verbally consent to be interviewed, for the interview to be audio taped and for the audio tape to be analysed. The interview will be audio taped, however all information will be treated as confidential and will be anonymised.

How long will the appointment last?

The group interviews will last approximately 60 to 90 minutes depending on how much information is spoken about.

What if I agree to take part and later change my mind?

You can withdraw from the study at any point by contacting the researcher below. You do not have to give any reasons for this and this will not affect your rights for any treatment from the service.

Ethical approval and confidentiality

This study has been approved National Research Ethics Service for the NHS and also by

Coventry University Ethics committee. A copy of the final report will be available in September 2011 and all participants will be able to receive a summary of the results.

The researcher contact details

Tina Oza Mistry (Trainee Clinical Psychologist)

If you wish to take part in the study or you have any questions about the study please contact the number above and leave your contact details with the secretary. The researcher will then contact you to arrange an appointment.

Yours Sincerely

Mrs Tina Oza Mistry
Trainee Clinical Psychologist
Universities of Coventry and Warwick

Appendix 9: Consent form

Title of the project: An Exploration of South Asian Client's access to Psychological Services within Oncology and Palliative care in the West Midlands.

Researcher: Tina Oza Mistry

Instructions:

Please read the following points and tick each box to indicate that you agree, and please sign and date below:

I give permission for my interview to be audio recorded.

☐

I understand that the tape will be stored securely and treated confidentially.

☐

I give permission for the tape to be transcribed and used as part of the research.

☐

I understand that the transcribed information will be stored securely and treated confidentially.

☐

I understand that I can request for a copy of the transcript at any time.

☐

I understand that I can withdraw from the study at any time.
If I withdraw from the study, the tape and transcript will also be destroyed.

☐

Signed:

Print name:

Date:

Appendix 10: South Asian participant Interview schedule

Thank you for participating in the research.

- I am interested in you and your experiences.
- There are no right or wrong answers.
- I will say very little and will be like a curious listener trying to get to know you.
- Please take your time to think and talk.

1. What is your age?

2. How would you describe your ethnicity?

(What is your country of origin?)

3. Do you practice/follow a religion and what is it?

(How religious would you say you are?)

4. What is your main/first language?

(What other languages do you speak?)

5. Where were you born?

(How long have you lived in the UK?)

6. Can you tell me about how you came to access the clinical psychology service?

(Who suggested it or how did you hear about it? How long ago was it? How were you feeling about it? What were your circumstances? What issues did you need support with? What was your/their health like?)

7. What other forms of support had you accessed before?

(What had helped you cope with emotional issues?)

8. What helped you to decide to access further support?

(What were the factors you considered? What was difficult about the decision?)

9. What did you already know about psychology services?

(What were your impressions? Where did you find this information from? How helpful or accurate was your pre-existing knowledge about psychology? Do you know anyone else that had accessed it?)

10. What was it like when you first made contact with the service?

(How did you feel? What did you think? How would you describe the process?)

11. How did you feel when you were accessing emotional support from clinical psychology?

(What did your friends/family think?)

12. What was your experience of accessing clinical psychology services?

(What was the psychologist like? How did they handle your issues? What were the facilities like? What was helpful and what was not helpful? What issues have stayed with you?)

13. In hindsight, If you did not access psychology services, where or who do you think you would have got your support from?

(Is there anyone else you can talk to apart from clinical psychology? What strategies did you use to cope with your distress?)

14. In your opinion, what are the psychological or emotional issues that affect people from your community when faced with cancer or palliative care?

15. Could you give me some possible reasons why people from your community may not seek psychological support?

(What factors would encourage them to seek help from psychology?)

16. What do you think needs to change to help people from your community to access psychological help?

Appendix 11: Key informant interview schedule

Welcome and thank you for attending the focus group which aims to explore South Asian client's access to psychological help within oncology and palliative care services.

The interview will last between 60-90 minutes, depending on how much is spoken about. The interview will be recorded and transcribed. All data will be anonymised and some quotes will be used in the final report.

- 1. What have your experiences been of working with South Asian patients and carers?** (At what point have they sought help? How do they present themselves to your service? How do they receive your services? Approximately how many South Asian patients have you seen?)
- 2. How do you think South Asian patients present when they are struggling with emotional/psychological issues?** (What type of issues do they struggle with? Who do their issues involve?)
- 3. What do you think are South Asian client's beliefs about receiving emotional/psychological support?** (How do they talk about their emotions/psychological issues?)
- 4. What do you think are South Asian client's attitudes and experiences are of help seeking for emotional/psychological support when faced with cancer or related illness?** (Where do they seek support from? How do they perceive specialist support?)
- 5. Where else do you think South Asian people receive/seek additional support from?**
- 6. Have you experienced differences between the South Asian groups?** (What differences are there between people from Pakistan and India for example? What are the gender differences? What are the generational and age differences?)
- 7. In your opinion, how can the psychological service help South Asian patients?** (What issues could the service provide support with?)
- 8. How do you explain to South Asian patients what the psychological service provides or may help with?** (What helps makes it easy to explain? What makes it difficult to explain? How do you explain what psychological treatment is?)
- 9. What do you consider when referring South Asian patients for psychological support?** (What factors stop you from referring?)
- 10. What are your opinions on the improvements that can be made to make psychological services more accessible to South Asian patients?**

Appendix 12: IPA procedure

IPA procedure (adapted from Smith, Flowers and Larkin, 2009)

Step 1. Reading and re-reading transcript and listening to the audio-recording at the same time. Recording own recollections in separate research diary.

Step 2. Initial coding which is noted on the right hand side margin. Descriptive noting which will pay particular attention to the participants meaning of things. In particular comments will include descriptive comments that focus on the content of what has been said. Also linguistic comments that explore the use of language and conceptual comments which interrogate and conceptualise the transcript. Interpretative noting to help the researcher understand how and why the participants responses.

Step 3. Developing emergent themes

Using the initial coding (step 2) the researcher develops themes that represent mapping interrelationships, connections and patterns between notes in step 2, which are expressed as phrases and are written in the left hand side margin.

Step 4. Making connections across emergent themes.

By writing up themes on post-it notes and organising themes using strategies such as abstraction, subsumption, polarisation, contextualisation, numeration, and function (see Smith et al., 2009).

Step 5. Repeating steps 1-4 with the next transcript and code in its own right, as it is important to allow for new themes to appear.

Step 6. Looking for patterns across all of the transcripts. This was done by laying the each transcript themes and comparing them against the other transcript themes. This process enables reconfiguring and relabeling of themes.

Appendix 13: Researchers position

Researchers Position

The lead researcher was a South Asian female, who was of Indian Gujarati heritage and practised Hinduism. This may be seen as an advantageous position for the South Asian participants to open up and talk about issues that they may have felt the researcher would have knowledge and understanding of the south Asian culture in general. However, the personal knowledge of South Asian culture, in particular experience of being Indian Gujarati and Hindu may also be a hindrance for the IPA analysis as the researcher may become fixed on particular identified cultural elements of emerging themes that are pertinent to the Researchers own culture .

The researcher was also on placement at the establishment where she was recruiting participants from. Participants may have altered their responses as the lead researcher worked within the psychological service. This position was advantageous as the participants were familiar with the lead researcher as they were identified to be part of the service. However, this may have limited the participants to be honest about the experiences from the psychological service. The researcher was new to the area of oncology and palliative care and had been learning about the elements that arise in psychological treatment and this placed the researcher within a non-expert role. The researcher did not have any particular theoretical models that they were aligned to however; they had an interest in systemic and community psychology to inform them on societal and cultural factors that affect the individual and takes into account social constructionist ideas.

Appendix 14: Example of initial coding

• medics didn't want to get it wrong

• waiting - tension

• Family united
family together
united

• Medics/doctors giving
difficult news

• medics/doctors not
sure of diagnosis
not sure extent of
cancer

• anger towards
medics

• want to know
what to do next -
fear of outcome of
diagnosis

• Family share
emotions - pain

35 time like, we check again and we do the biopsy". And they requested the lump to make sure
36 then after two weeks I went and they did the biopsy and she went again to get rechecked
37 then we have to wait for two weeks for the results. We all waited 2 weeks for the results
38 went, me, my daughter and my sister and my husband we because family want to get the results
39 all went up there. They called us for the results. And we they all want to get the results
40 all sat there and the doctor was sat there in the room. They the family sat together with the doctor
41 said that "we see the cancer cell". They said "we seen the doctors reported that they found cancer cells
42 only tiny bit" they told me, "we don't know what size but doctors reported small number of cells and they
43 we only seen little." And I argue with that happen before are unsure what size the cells are but they have only
44 what happen and they said "that was nothing they seen seen a small amount - feel angry that this situation
45 only the shadow. They told me like that. They told me was happened before as they reported nothing last
46 they seen cancer cell but they don't know how big is it. time. They do not know how big the cancer cells
47 We seen only the tiny bit. Well the question is come is they have only reported seeing a small part
48 what you gonna do? If it's a lump you going to take it out. She wants to know what next? what are they going
49 only lump? or take the whole breast off? It was a big step. to do next? extraction of lump or whole breast
50 That day soon as we all find out we was all, we don't to be removed - overwhelming situation
51 know we all cry soon as we heard the cancer my husband while family didn't know what to do, shock
and tears, husband because of the cancer word.

• family find it difficult
 share - pain set in
 to family - can cope
 • support systems available
 straight away
 • space provided to
 sink in
 • emotional support is
 what
 • there is hope
 • people try to give me
 hope -
 • fear of death
 Cancer - death
 • can't cope -
 • people try to give
 hope
 • decision making
 is difficult
 • family decision
 making

is run out from the room, I cry my daughter and my
 sister all cry. They took us to the another two ladies doing
 the job for the cancer, in the hospital. G and S who had
 experience cancer. We finish from doctor and doctor said
 "It's too hard for you to take it so we stop here." And
 they took it to another room, we was talk to them they
 gone the same thing happen to me. We was talking to
 them. And they was really helpful. The one woman says
 10 years now and another one say I had 8 years
 experience, so you be alright, everybody said that. But my
 mind in there is still cancer word. I didn't take nobody, I
 listen. In my mind they talk to me they give me lot of
 strength and everything. But in my mind is the cancer
 word. I can't think anything. I keep crying. Week later
 they call us they say you have to tell us what you gonna
 do. I didn't tell them. I tell my daughter if its little they
 take the lumps out but they say you can't do that. If I say

husband escapes from situation, despair
 from whole family
 medicals taken patient to people also experienced
 cancer
 Doctor understand the pain and do not understand
 they were provided support from people who had
 experienced cancer
 it was useful to hear from experienced survivors
 They haven't lived + survived cancer for a long time
 People believed she would be fine + recover - hope
 Can't shake off the reality of cancer + death
 Attempt to make sense of information however
 find it hard to take it in
 People try to support her however no matter
 what the fear is still present + fear - crying
 Give time to think about treatment procedure
 chose not to make a treatment decision then
 speak to daughter about options of treatment

Appendix 15: Summary of protocol for using IPA with focus group data

Summary of protocol for using IPA with focus group data (Palmer et al., 2010)

1. Objects of Concern and Experiential Claims

- a. Pick out experiential claims and concerns as they appear in the transcript.
- b. Summarise these, and sort into emergent patterns.

2. Positionality

- a. Explore the role played by facilitators, keeping track of questions, permissions, encouragements, redirections, etc. (What is their perspective, stance, position?)
- b. Explore the function of statements made by respondents. (What is their perspective, stance?)

3. Roles & Relationships

- a. Examine references to other people: What roles and relationships are described? What sorts of meanings and expectations are attributed to these relationships?
- b. What are understood to be the consequences of these?

4. Organisations & Systems

- a. Examine references to organisations and systems: How are they described? What sorts of meanings and expectations are attributed to these?
- b. What are understood to be the consequences of these?

5. Stories

Examine the stories told by participants: look at the structure; genre; imagery and tone. What

does each story achieve? How do participants support or impede each other to share their

experiences? What temporal referents exist?

6. Language

Throughout stages 1–5, monitor language use, paying particular attention to use of metaphor,

euphemism, idiom, etc. Consider:

a. Patterns

Repetition, jargon, stand-out words and phrases, turn-taking, prompting – are these identified

in individuals or the whole group?

b. Context

Impact on language used; descriptions of feelings/emotive language; jargon and explanation

of technical terms; impact of facilitator.

c. Function

How/why is certain language being used? (e.g. to emphasise/back-up a point, to shock,

to provoke dis/agreement, to amuse/lighten the tone?)

7. Adaptation of Emergent Themes

Return to the emergent themes from step 1b. and adapt them according to the work done subsequently. Answering the following questions will help:

- a. What experiences are being shared?
- b. What are individuals doing by sharing their experiences?
- c. How are they making those things meaningful to one another?
- d. What are they doing as a group?
- e. What are the consensus issues?
- f. Where is there conflict? How is this being managed/resolved?

8. Integration of Multiple Cases

Where more than one focus group has taken place, integrate work done with each to build up an overall analysis of the topic under investigation. Data should be checked to ensure sufficient

homogeneity between focus groups to allow for successful integration. To draw the analysis to completion:

- a. Pick out commonalities and stand-out differences between groups drawing out superordinate themes.
- b. Frequently revisit the transcripts to check themes in relation to original claims made to help ensure accuracy.
- c. Consider the analysis in the wider context of existing relevant theories, models and explanations.

Appendix 16: Integration of focus group data

	Focus group 1	Focus group 2	
Emergent Themes (1)	Family and language are communication barriers Young vs. old generation Consequences of barriers Gender differences Asians are different Asians are the same Conflict with profession Own service challenges and reflection Service barriers	Asian Impact and response to cancer Service barriers and approach Asian Family barriers Asian culture (inc religion) & White culture Service challenges with Asians Younger vs. Older generation What needs to change?	
Emergent themes (7)	The challenges we face (communication, family, lack of understanding/awareness) Impact of challenges (practice and conflict) What we have learnt and what can we do (reflection on own service and changes)	Our Service challenges (family, culture, and service barriers, generation differences) Asians and cancer impact Changes are needed	Our Challenges (service) Their challenges (Asian barriers)
Positionality	Supportive of each other's experience reflective on practice, facilitator; limited interaction some prompts	Facilitator: limited prompts, summarised, interested in psychological impact limited inside knowledge (white) reflective on own practice opinionated- critical about services and Asians (sensitive to old generation)	
Roles & Relationships	Positive and negative experiences with families	'We, us' insider knowledge	
Organisations & Systems	More engagement from services is needed	Critical of medical services Limited resources unsuited to south Asians	
Stories	Challenges and impact on delivery of service	Difficult challenging experiences with Asians accessing services Experiences of Asians being resistant	
Language	Informal, use of spoken word to illustrate real examples, honest opinions	informal slang language use of Punjabi personal opinions 'I think'	

Appendix 17: Summary of quotations

Superordinate Themes	Emergent theme	Example (participant)
Pre-existing beliefs	Psychological and mental health services	<p><i>[Community outreach worker] said to me that this doctor (clinical psychologist), what we tell you, and we can support you, but this one will explain and make you understand everything what is happening to you, what your difficulties are. She will properly make you understand. What was happening in your mind, the main question was that for them, what was happening in your mind. (Indumati: 275-281)</i></p> <p><i>(Pause) And I don't think persona..., erm now, that psychiatrist or psychologist's see mad people. At the time, I didn't want to feel I was going mental myself. (Navpreet 122-124)</i></p> <p><i>If they couldn't help my mum how could they help me? (Navpreet; 133-134)</i></p> <p><i>when she was Asian I thought if she's Asian she's not gonna know how I feel and with my family all being Asians they don't know what I'm going through. They can't erm. So is she going to be? (Saadia; 108-111)</i></p> <p><i>No, I know they're there cos you know not just for cancer but I know they're there for other things as well. but I never thought I'd go out and see one because you know as I said I feel that my all I need to do is at the end of the day is to deal with any problem is to speak to Allah. (Saadia; 152-156)</i></p> <p><i>I can't really remember as I said I was scared that she was Asian one, and was scared that I couldn't open up. (Saadia; 171-172)</i></p> <p><i>But my first impression was that she's Asian she couldn't understand what I was going through. And can I talk to her will she understand? (Saadia; 176-178)</i></p> <p><i>Well I already knew about psychologists anyway at G H. Years and years ago when I was in a bad marriage basically I had a psychologist seeing me then really. (Sharanjeet; 34-36)</i></p> <p><i>Because I remembered my mum going through things I didn't want to go down that road where I was constantly on pills do you know what I mean? (Sharanjeet; 57-59)</i></p>
	Mental health and self	<p><i>I was thinking that I was normal and I'm in control. I didn't talk about it much to people. I know I wasn't in control at the time but I wanted to be. I was scared to go to, I didn't want to be classed as, she's under the...everything with psychologist, was a psychopath you know, I dunno why. You know mad person. I didn't want to be classed at that. I didn't want to go there. (Navpreet;</i></p>

		<p>57-62)</p> <p><i>She thought that I was dealing with it by myself at the same time as I said I was dealing with it God alone. I think she basically pushed me that way. I didn't look for support myself or ask for S to see me. I think mostly N pushed me that way. So it's all her doing really. (Saadia; 143-147)</i></p> <p><i>Well I was hoping she could help me I wasn't thinking all negative and think oh my god there's something mentally wrong with me. Because obviously going through what I did and having counselling before. (Sharanjeet; 48-50)</i></p> <p><i>I didn't actually I didn't feel like there was some sort of what can you say....you know and then label you. I wasn't worried about things like that so ...I wasn't concerned about that, I just wanted to get the help. (Sharanjeet; 54-56)</i></p>
Psychological journey of cancer	Diagnosis and treatment	<p><i>But my mind in there is still cancer word. I didn't take nobody, I listen. In my mind they talk to me they give me lot of strength and everything. But in my mind is the cancer word. I can't think anything. I keep crying. (Indumati; 61-65)</i></p> <p><i>Otherwise, I know that the cancer is a big thing it's not a little thing erm it's a big big thing and it's not easy to deal with. (Saadia; 160-162)</i></p> <p><i>After I was, I don't know where I am. I didn't know what to do where to go. (Indumati; 104-106)</i></p> <p><i>It's been out, I was relief. (Indumati; 108)</i></p> <p><i>After that I was relieved, but I felt like I had lost one of those parts. I lost it. Afterwards it was just shock, the chemotherapy, radiotherapy. They give me all leaflets, video, everything and books I can read. The more I read it the more I get frighten. I really frighten. (Indumati; 111-115)</i></p> <p><i>I didn't know what to expect to be honest with you and to be honest with you when you are grieving, as I was grieving. Just like losing an arm or your leg, you know losing your breast. I didn't expect anything. (Navpreet; 182-185)</i></p> <p><i>And they said it was cancer. But at that time I was in disbelief I thought it can't be cancer its gotta be a cyst or something. But they said straight away it was cancer. So I came back home thought again about it and thought do I want some more biopsies, cos that's what they said to me have a couple more biopsies and we'll diagnose it properly, but we are sure it is cancer. Just I was in disbelief. And then I did go for a couple more biopsies to distinguish that it was cancer. (Saadia; 26-33)</i></p> <p><i>And just from then on it was one thing after another so (Saadia; 33-34)</i></p>

		<p><i>the type of cancer that I was diagnosed with there is a tendency for it to come back. But where it comes they don't say. They don't know. It's just a waiting game now. But for the moment I'm all clear and I'm happy with that, so I'm just coming to terms with it. (Saadia; 89-93)</i></p> <p><i>Well after my illness really, cos I was having a lot of panic attacks about it, anxiety and getting depressed and emotional. (Sharanjeet; 20-21)</i></p> <p><i>I mean things have changed, I mean when I was diagnosed I was thinking oh my god this is it you know. It's coming to terms with that really, I don't know. (Sharanjeet; 337-339)</i></p>
	Meaning making	<p><i>My first question to Dr S was why me? Out of all the people, I was the only one to be found. (Indumati; 299-301)</i></p> <p><i>And then again I was in a lot of disbelief that I could have cancer as I thought it was a history thing. That if it's in the family, then you would get it, but no one in my family's got it so I would be the first one. I thought... well why me? You know erm everybody else was there why particularly me? And I couldn't get to terms with it. (Saadia; 39-44)</i></p> <p><i>You wouldn't believe that after this had happened to me everything I done is gone, my religion completely blank. I told Dr X (Clinical psychologist) this as I had so much faith in Sai Baba [Hindu Saint] and Ambaji [Hindu Goddess], I believed so much. But when I heard the cancer, I would ask God why me? What did I do wrong? It all went out of my mind. (Indumati; 316-322)</i></p> <p><i>So I started a lot of praying. Which I do, and confided in God quite a lot. So my prayers were quite extensive and I just got stronger through it and... (Saadia; 48-50)</i></p> <p><i>I continued with that praying so I confided in Allah in my prayers and it helped me quite a lot. (Saadia; 123-125)</i></p> <p><i>I feel no I want to be in comfort with God because at the end of the day He gave me this disease or whatever you call it and I believe He is testing me to see how much I can take of it. How I confide in Him and how I ask for His help. (Saadia; 128-132)</i></p>
	Psychological therapy	<p><i>What it felt like was the pain that I had kept inside me, I took it all out. Because I had filled it all inside and sat with it. (Indumati; 291-292)</i></p> <p><i>And I told her a bit about myself at the time, you know me background and that, and erm. So she knew where I was coming from. But I felt relieved, that I knew I could talk to her and I knew that she'd be there if I needed her. So I felt a bit better. (Navpreet; 119- 122)</i></p> <p><i>let me just speak and spill out I think somewhere along the time I did break down and she did listen to me quite a bit. She listened and I suppose I needed someone to listen</i></p>

		<p><i>to me. (Saadia; 115-118)</i></p> <p><i>And I think I was there quite a while it was just the way she was the way she spoke to me. The way she guided me the support there. I thought she does understand cos obviously she seen other people as well and she knows what I'm saying and talking about. (Saadia; 186-190)</i></p> <p><i>I think with me as well, talking helps I feel like I'm being reassured you know I'm not going mental or anything. (Sharanjeet; 59-60)</i></p> <p><i>I mean I can go to the groups and I can go and seek help if I needed. I find that my help if I sit at home and pray I get a lot of help from there than when I go outside. (Saadia; 125-128)</i></p> <p><i>I came out feeling positively actually, I mean when I first went in there I was panicking and when I saw her there were tears, cos I was finally talking to someone for the first time. (Sharanjeet; 96-98)</i></p> <p><i>So I felt emotionally drained but glad that I had somebody to speak to. (Sharanjeet; 100-101)</i></p> <p><i>It's when you go to a clinical psychologist and they understand what you're talking about and they can explain well I'm feeling like this and why do I feel like this they explain it to you and even your closest family can't even explain that to you. (Sharanjeet; 108-111)</i></p> <p><i>And we've got an away day from work and I missing that because I'd rather go to the survivors group. I told my boss and they agree with me cos they know that's going to benefit me more. (Sharanjeet; 146-148)</i></p> <p><i>So I do think it's quite important and all the information they give me as well. I read through it and plus I know I've got that to go back on. And I also know if I ever feel like I still need further help after the groups have finished I can still go back to S. So I feel like I've got something there. If I still feel like I need the help. (Sharanjeet; 150-154)</i></p>
	Strengths and hope	<p><i>I felt like that part of me is gone. Every 27th January I think, every time. Two years have passed and I haven't realized. (Indumati; 309-311)</i></p> <p><i>And since I've been going to the group meetings... and also i don't forget things people tell me and so when S told me things they stay at the back of me head. So now you know there are days that I don't think of my illness. (Sharanjeet; 179-182)</i></p> <p><i>I've got to live my life, I can't keep worrying about it cos then I'm not going to then really enjoy my life so I try and you know I have good days and bad days. (Sharanjeet; 184-187)</i></p> <p><i>But at least I am still here. And that's the main thing that I have to keep looking at. (Sharanjeet; 256-</i></p>

		258;)
Family, friends, and others	Emotional effect on family	<p><i>My husband spoke to the nurse and began to cry...(Indumati; 179-180;)</i></p> <p><i>I was like Patricia, I'm so scared to go to the gym and I'm not normally. (Navpreet; 248-249;)</i></p> <p><i>I think my dad was scared at the time that's why he was screaming and shouting at the time and that was his way of, he didn't know what to say to me at the time. (Navpreet; 560-562)</i></p> <p><i>...I didn't know what it was at the time. As far as I was concerned I was going to have the operation and get back to work. I didn't realise the trauma that I was going to go through. (Navpreet; 660-662)</i></p> <p><i>I'm not with it at the moment but you come to live with it don't you. (Saadia; 44-45)</i></p> <p><i>erm I had the support of the family and all that they were all there but while they were all there I still felt I was alone. (Saadia; 46-48)</i></p> <p><i>I was getting quite scared of things cos obviously your going along life normally and yeah you have these little things that happen to you and when this happened it sort of frightened me a bit you know, actually quite a bit really. (Sharanjeet; 64-67)</i></p> <p><i>So when I came home and I was just looking forward to just enjoying myself and I didn't think this was all gonna hit me when I go out. (Sharanjeet; 79-81)</i></p> <p><i>And generally I am quite an optimistic and positive person but this illness has knocked me really. (Sharanjeet; 113-114).</i></p> <p><i>Well I know it is an illness but it's not life threatening do you know what I mean. But like the illness that I've had did freak me out and would freak anybody out. (Sharanjeet; 121-123)</i></p> <p><i>and what was happening was I was keeping myself to myself. I was wrapping myself up in bubble wrap basically. Because I had been in hospital for so long I was too scared to go out. And I suppose the other reason why I went for the help was I thought oh god I'm never gonna go out if I stay like this and that freaked me out a bit cos I'm a shopping here and going there buying clothes .. I can't at the moment but... (Sharanjeet; 131-137)</i></p> <p><i>You know the thought processes that S goes on about when your thoughts start going into one direction and you try and divert it to another. Cos I'd forgotten how to do that. Cos I was so consumed with what I was going through at the hospital. (Sharanjeet; 167-170)</i></p>

		<p><i>all this time before the world is fine and then all of a sudden you've had this illness and you think God it's a dangerous place out there, and you worry about this and you worry about that. (Sharanjeet; 172-174)</i></p> <p><i>when your diagnosed with an illness your file sort of comes to the front and what you've now gotta do is slowly get it... (Sharanjeet; 177-179)</i></p> <p><i>And then there are days when I'm watching telly and I'm perfectly alright and then all of a sudden it goes bang and I'm like oh my god and I get scared. (Sharanjeet; 182-184)</i></p>
	Family is there for practical support	<p><i>We all went, me, my daughter and my sister and my husband we all went up there. (Indumati;37-39)</i></p> <p><i>That day soon as we all find out we was all, we don't know we all cry soon as we heard the cancer my husband is run out from the room , I cry my daughter and my sister all cry. (Indumati; 50-53)</i></p> <p><i>My daughter say, and my husband say it's your body and doctor told me it's your body you have to choose it, nobody gonna tell you what to do. So my daughter and my husband says what's the best for you, we won't interfere. (Indumati;83-87)</i></p> <p><i>She'd say you have to face up people. Why do you come here? I'd say because they are all like me that's why. I used to wear the scarf and hat and go out to where I needed to but apart from that I stayed at home. I never left home. (Indumati;341-345)</i></p> <p><i>my friend P came you know from the states, she knew I had people around me that would support me like my friend who came and visited me and spent couple of what's its ten days with me and got me back in the gym. (Navpreet; 245-248)</i></p> <p><i>But my brother, my sister in law and my two nephews have been brilliant; both my nephews are doctors as well. And they did agree with seeing a psychologist as well cos I did talk it out with them as well, and my brother. And so I do still have a lot of support from them when they came over. (Sharanjeet 194-198)</i></p> <p><i>You know to live with somebody who comes out of hospital constantly paranoid 24/7 I know it'll be wearing for me. Cos every bodies human. But he's been so patient. And he's supported me going to the group, to see S, to have my counselling from G. He's really supported me and that helps. (Sharanjeet 292-206)</i></p> <p><i>And my aunties, my mum's sister all she does is kisses and hugs me, she's like always god this and god that, you pray to god and thank god that you're alive. She's a good aunty. I don't talk to her how I feel. She more god this god that, that's what Asian people do. (Navpreet; 595-599)</i></p>

	<p>Family is not there emotionally</p>	<p><i>When I went to chemotherapy there were all these patients sitting and they were all taking and you can't stop it from going in your ears.(Indumati; 150-152)</i></p> <p><i>...a few people overheard our Gujarati people. You know how our Gujarati people are, one to two, two to three and three to four , this way the word gets around and from that my closest (relatives) as well. So from this my maternal uncle and maternal aunts came to see me one evening and they said P, my husband was crying so much and they said I what is the problem? (Indumati;182-188)</i></p> <p><i>I couldn't speak to anyone. I turn to my husband, my husband cried, and I turn to my daughter my daughter cried, my sister too. Who could I turn to? I couldn't face up to it with nobody. (Indumati; 292-296)</i></p> <p><i>My family, it was like my sister saying 'you haven't had breast cancer, its pre-cancer', she kept on going and I just had me breasts off and lymphnodes removed 'it's not cancer' she said. And at that stage, it was shut up don't talk about it. I just couldn't talk about it. (Navpreet; 81-84)</i></p> <p><i>They hide it for me or do I hide it. When I meet them on the bus they say I are you alright how are you? Another lady same thing happened to her just over a year ago they act like queens don't talk they don't do anything. (Indumati;449-453)</i></p> <p><i>Erm, my dad didn't know, it s too embarrassing to talk to him you know, it's bad enough having breast cancer. (Navpreet; 356-357)</i></p> <p><i>...but looking back of when I was growing up, I think it is embarrassing. I do find that some Asian families find it difficult to talk about, they seem petrified even. (Navpreet; 584-586)</i></p> <p><i>It's your femininity. It's all the stuff on TV; you don't talk about boobs, or sex. In the Asian community I know, we didn't talk about that it's not the thing to do. (Navpreet; 604-606)</i></p> <p><i>They probably don't access support if they haven't received any support from their family, and also not the medical profession. (Navpreet; 625-627)</i></p> <p><i>Also family don't want you to access it and Sometimes a stranger coming in your life, oh then the family think there's a white person in the house who is it. I know my dad used to be like that very strict. And my dads used to say don't trust the English people they may just one day kick us out of this country.(Navpreet; 631-636)</i></p> <p><i>Whereas in the past they would have asked questions, they would have been very suspicious. (Navpreet; 640-641)</i></p> <p><i>But I've never opened up with them never mingled with them related with them to ask about you know anything to them I haven't. So I don't really know what they would</i></p>
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	Generational differences	<p><i>Be more open, like how I have expressed to you we must move forward younger can face up. By neighbour are the opposite, she's an English woman only 23 with two children and in her family there is cancer, mum gran, nan, everyone in the family. Doctor told her that she has breast cancer. That girl is so strong, she said to the doctor operating might take it off two I don't want it to come back. (Indumati; 463-470)</i></p> <p><i>I would say the language barrier, and the elderly they don't believe in things like psychology. They think that you know if you speak to another person or speak to member of the family that's quite efficient for them. And they deal with it that way. They don't believe in these services that are being offered to them that might be a reason why. (Saadia; 220-225)</i></p> <p><i>In today's society it's changed a lot, families are becoming a lot more westernised. (Navpreet; 624-625)</i></p> <p><i>And now because you are getting your second and your third Asian generation coming through a lot more people are becoming educated its becoming more accepted to mix.(Navpreet; 638-640)</i></p> <p><i>Cos it's a sensitive subject, I know the older generation</i></p>

		<p><i>are very strict in their thinking. You don't want to point out breasts in front of all; (Navpreet; 674-675)</i></p> <p><i>But the elderly it's just like one of those things you just get on with it, don't need a psychologist. They're for the English people and not ourselves. And why go to them. (Saadia; 252-254)</i></p> <p><i>but older generation their a bit too set in their ways, aren't they. And some of them can't speak English so they're not going to access it. There's a language problem (Sharanjeet; 265-267;)</i></p> <p><i>The older generation the women aren't so, if a woman was having mental health problems they would let her go see a professional now would they. Or if she said she was going to. It's that sort of thing; they'd take them off to India to treat them there, going to see like a priest or something. They don't believe in going to see... I don't know...I can't explain it. Or they feel it's a bit they don't want other people to know. (Sharanjeet; 283-289;)</i></p>
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